Dementia Care and Quality of Life in Assisted Living and Nursing Homes

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STAFF FOR THIS ISSUE

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Cover Photograph—Aaron Itkin looks back on a fulfilling life—Janice, his bride of 56 years;
12 healthy, happy grandchildren; a successful career in the Chicago commodity exchange—and
looks forward with enduring hope that the Cubs will one day win the World Series.
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Introduction: Dementia Care and Quality of Life in Assisted Living and Nursing Homes

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Elizabeth Heck, MSW, LCSW,[4] Katie Maslow, MSW,[5] and Richard Schulz, PhD[6]

It is well recognized that the number of older adults who suffer from dementia has been increasing and will continue to do so over the coming years. In fact, nothing short of a three-fold rise in the number of people with Alzheimer's disease is expected to occur between 2000 and 2050, and those with moderate or severe disease may number as many as 6.5 million midway through the century (Sloane et al., 2002). As the severity of dementia increases, families face challenging caregiving demands, and many find residential long-term care to be the best option for ongoing oversight. Historically, nursing homes have been the primary setting for the institutional care of older adults. During the last decade, however, their prominence in providing care for individuals who do not need medical services has been challenged by the growth of residential care/assisted living (RC/AL)—facilities or discrete portions of facilities that are licensed by the states at a nonnursing home level of care, and provide room, board, 24-hour oversight, and assistance with activities of daily living. Recent estimates indicate that 23% to 42% of RC/AL residents have moderate or severe dementia, as do more than 50% of nursing home residents (Zimmerman et al., 2003). The number of RC/AL and nursing home beds exceeds 800,000 and 1.8 million, respectively (Institute on Medicine, 2001), suggesting that well more than 1 million individuals with dementia already reside in these settings.

The matter of "quality" of life for individuals with dementia has been increasingly recognized during the last decade, and countless textbooks and manuals have been written to provide guidance on enhancing quality of life (see, for example, Fazio, Seman, & Stansell, 1999; Kovach, 1996; Volicer &

Bloom-Charette, 1999). Efforts to define and measure this multidimensional component have progressed as well, and there now exist numerous valid and reliable instruments to do so (see, for example, Albert & Logsdon, 2000). What has been absent from the field is the study of quality of life for individuals with dementia in long-term care settings—both nursing homes and RC/AL facilities. Without this information, it has not been possible to evaluate components of care that relate to better quality of life. In this context, the work conducted by the Collaborative Studies of Long-Term Care (CS-LTC) constitutes a significant contribution to what is known about quality of life and its correlates in long-term care. Another contribution of the work conducted by the CS-LTC is its basis in community-based participatory research, which maximizes its utility for practice and policy. As detailed in the following "Perspectives of the Alzheimer's Association," the Association is using this information as the basis for its evidence-based consumer education, advocacy, and staff training efforts. Thus, the work presented in this issue is a necessary step toward the improvement of care and the quality of life for persons with dementia.

The Collaborative Studies of Long-Term Care

The CS-LTC, initiated in 1997, is a series of multistate projects that have studied almost 5,000 residents in more than 350 RC/AL facilities and nursing homes, with the goal of better understanding issues related to quality of life and quality of care. The CS-LTC was initiated in response to the proliferation of RC/AL facilities, to address the paucity of information regarding the needs of their residents and the care that they receive, especially in light of the great diversity among these facilities. A detailed overview of the structure and process of RC/AL, obtained through the CS-LTC, is available elsewhere (Zimmerman et al., 2003; Zimmerman, Sloane, & Eckert, 2001).

The Dementia Care study reported in this issue is one of the CS-LTC projects, which collected data

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from 421 residents in 45 facilities across Florida, Maryland, New Jersey, and North Carolina between 2001 and 2003. These four states were selected because they exhibit differences in the structure and financing of RC/AL and nursing home care. A multilevel sampling frame was used to select facilities and residents for participation. Within each state, a region of contiguous counties was identified that represent the state, and a sampling frame was constructed consisting of all nursing homes and licensed facilities within each region. RC/AL facilities were stratified into three types to assure inclusion of the broad range of options: (a) facilities with < 16 beds; (b) facilities with ≥ 16 beds of the "new-model" type that offer add-on services, cater to a more impaired population, and/or provide nursing care; and (c) "traditional" facilities with ≥ 16 beds, not meeting new-model criteria. Sampling all three types of facilities assured broad representation of facilities and variability in resident case-mix, policy, and care provision.

The Dementia Care project was based on a purposive stratified sample of 45 facilities, 33 of which were already participating in the CS-LTC and were known to have variability in some components of dementia care (e.g., acceptance of behavioral symptoms). The Alzheimer's Association identified an additional 12 facilities that incorporated features of particular interest (e.g., did or did not have responsive owners, a special care unit, individualized care, daily programming, staff training, and/or select environmental features). Within facilities, the primary criteria for selecting resident study participants were being aged 65 or older and having a diagnosis of dementia; for purposes of efficiency, facilities with fewer than 2 eligible residents (in facilities with fewer than 16 beds) or 13 eligible residents (in all other facilities) were excluded from the study. Eligible facilities were enrolled in a manner that maintained stratification of facility type across states. Twenty-two facilities (33%) refused to participate, but they did not differ from participating facilities with respect to type, size, or location. The final sample included 14 facilities (31%) with fewer than 16 beds, 11 (24%) traditional facilities, 10 (22%) new-model facilities, and 10 (22%) nursing homes. Twelve facilities were from North Carolina, and all other states had 11 facilities.

Residents were randomly selected in each facility from among those 65 years of age or older who had a diagnosis of dementia, excluding those who had a primary diagnosis of Huntington's disease, alcohol-related dementia, schizophrenia, manic-depressive disorder, or mental retardation. To maintain representation across facility type, a maximum of 4 residents per smaller facility and 19 per larger facility was established. A total of 575 eligible residents or their families were approached for consent. Of these, 421 (73%) agreed to participate, 66 (11%) refused, and 88 (15%) were unable to provide consent and had family who were unreachable.

Data collection from residents and staff was conducted on-site, and family members were contacted by telephone. Interviews were conducted with each resident; his or her family member; the direct care provider who provided the most hands-on care and knew the most about the resident's care, health, mood, and daily activities; the supervisor (the staff member above the direct care provider level who knew the most about the resident); and the facility administrator (to obtain facility-level data). Additionally, data collectors observed residents during one meal, and during the course of a single day at 5-min intervals during three 1-hr observation periods; also, the physical environment of each facility was observed.

The design of the Dementia Care project allowed a comparatively modest number of residents and facilities to be sampled; consequently, the study's power to detect some associations is limited. However, the sample included facilities with large proportions of residents with dementia (the average reported percent of residents with a diagnosis of dementia was 55% to 57%) and a relatively high proportion of facilities with Alzheimer's special care units (54%). Thus, while findings related to the prevalence of resident and facility characteristics are not meant to be generalizable to all facilities or nursing homes, the study may well represent dementia care as it is currently being practiced. Further, although the number of facilities and residents sampled was necessarily limited, the patterns of associations found in this study are not expected to differ dramatically in other facilities.

Organization of the Special Issue

This special issue includes 16 manuscripts, grouped within four headings. Not all are derived from the CS-LTC Dementia Care study. The first four manuscripts address conceptualization, measurement, and correlates of resident quality of life, and include articles focusing on a single quality-of-life measure (Brooker; Samus et al.) and comparing multiple measures (Edelman, Fulton, Kuhn, & Chang; Sloane, Zimmerman, Williams, et al.). They discuss the different perspectives of what components constitute aggregate quality of life and the measures and methods of data collection that arose from these concepts. Because of these differences, correlations between measures are moderate at best, suggesting that multiple indicators are needed to adequately reflect the richness of life.

The next six articles are brief reports from the CS-LTC Dementia Care study, focusing on discrete domains of quality of life. Recognizing that aggregate measures of quality of life do not easily translate to practice recommendations, a liaison panel convened by the Alzheimer's Association suggested focused attention to six critical areas—depression, behavioral symptoms, mobility, pain, food and fluid intake, and activity involvement—each of which is

the topic of a brief report. All reports are constructed with a similar format, addressing the prevalence of problems within the domain, methods for assessing and treating residents in the domain, and staff training in the domain. Associations between domain attributes and resident and facility characteristics also are reported. The findings clearly demonstrate room for improved outcomes in these critical areas: between 50% and 60% of residents with dementia display behavioral symptoms and low food and fluid intake, 20% to 25% exhibit depression or pain, and 14% have high mobility limitations. Staff assessment and perception of impairment is highest for behavior, but lowest for fluid intake, and perceived success of treatment is highest for pain management. Between 50% and 75% of administrators report training the majority of their staff in all domains of care, and more than 75% of staff feel adequately trained to assess and treat each domain. Based in part on the findings of these studies, the Association has focused its first set of practice recommendations on pain, food and fluid intake, and activity involvement, and recommendations in other areas are forthcoming (Alzheimer's Association, 2005).

The next four articles are special topics related to quality of life and quality of care. The first three use data from the CS-LTC Dementia Care study, addressing two important contributors to quality of life in RC/AL facilities and nursing homes: families and staff. The first discusses how families fill care provision gaps, concluding that they tailor their involvement in accordance with the needs of the resident and the setting (Port et al.). The second two (Zimmerman, Williams, et al.; Winzelberg, Williams, Preisser, Zimmerman, & Sloane) address staff attitudes, stress, and satisfaction, with findings indicating that person-centered attitudes and more staff training relate to higher quality-of-life ratings and worker satisfaction. The fourth is an ethnographic study, examining issues that relate to transitions into, out of, and within RC/AL, for residents with dementia (Mead, Eckert, Zimmerman, & Schumacher).

Two additional studies specifically address the relationship of care to quality of life and resident outcomes. The first is based on a larger CS-LTC study of 1,252 participants, and compares outcomes for residents with dementia in RC/AL facilities and nursing homes, examining mortality, hospitalization, morbidity, and change in functional status over one year. With the exception of residents with major medical needs, outcomes did not differ significantly across the two types of settings (Sloane, Zimmerman, Gruber-Baldini, et al.). The second article is a comprehensive examination of structural and process elements of care in the CS-LTC Dementia Care study and how they relate to 11 measures of quality of life, including change in quality of life over 6 months. Findings from this study have important implications for staffing and facility policies and practices, including staff attitudes and training (Zimmerman, Sloane, Williams, et al.).

Research in quality-of-life assessment and care in RC/AL and nursing homes is in its infancy. Sample size limitations in the work presented in this issue restrict the ability to conduct complex model testing, and the cross-sectional nature of much of the data limits the ability to draw causal inferences. Ideally, larger and longitudinal studies will be conducted across the range of long-term care settings such as those included in this issue, using admissions cohorts and monitoring quality of life and determining the components of care that relate to quality of life from the moment their influence begins. As will become clear through the information presented in the articles to follow, such an undertaking will require multiple measures; further, it should be conducted in close collaboration with community partners who can advise on the practicalities of care provision and help assure that resulting information can be used to improve practice and policy. Given the increasing numbers of individuals with dementia who reside in assisted living and nursing homes, the importance of this effort cannot be overstated.

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Dementia Care and Quality of Life in Assisted Living and Nursing Homes: Perspectives of the Alzheimer's Association

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In funding the Collaborative Studies of Long-Term Care (CS-LTC) Dementia Care study that is the basis for most of the articles in this special issue of *The Gerontologist,* the Alzheimer's Association hoped to learn more about measuring quality of life in people with Alzheimer's disease and other dementias. The Association also hoped to learn about care practices and other factors associated with quality of life to support our efforts to develop guidelines for dementia care in assisted living and nursing homes. The study findings, as reported in this issue, exceeded our expectations. The inclusion of findings on the same topics from studies funded by the National Institute on Aging, Mather Institute on Aging, and others adds to the value of the special issue, making it a source of important new knowledge about Alzheimer's and dementia care.

The CS-LTC Dementia Care study involved several firsts for the Alzheimer's Association. In 2000, after the Association's Medical and Scientific Advisory Board decided to fund Dr. Sheryl Zimmerman's investigator-initiated proposal for a study of quality dementia care in assisted living, another Association division, the Program and Community Services Division, decided to add substantial funding to expand the scope of the study. This was the first time in the history of the Alzheimer's Association that a part of the organization other than the research grants program chose to fund a team of researchers.

In another first, we asked Dr. Zimmerman if her research team would be willing to accommodate a liaison panel, a group of Alzheimer's Association chapter staff and national board members that we thought would increase our understanding of the

study and its implications for policy and practice. The research team was willing and actually gave us much more than we requested. The liaison panel participated in three 2-day meetings with the research team and helped to identify areas of care for special attention in the study and the later analysis of its findings. Having the liaison panel required a commitment of time and resources from the panel members, the research team, and national Association staff. From our perspective, the time and resources were well spent.

Measuring quality of life in people with dementia is difficult and, in fact, is usually not done. The CS-LTC Dementia Care study tested many ways of measuring quality of life. Residents with dementia who were thought to be able to respond (those with Mini-Mental State Exam [MMSE] scores of 10 or higher) were asked about various aspects of their quality of life. Nursing home staff members and family members were interviewed, and several observational methods were used. The Association was particularly interested in Dementia Care Mapping (DCM) and provided additional funding to include DCM as one of the observational methods.

Findings from the CS-LTC Dementia Care study show that conclusions about residents' quality of life differ significantly, depending on who is asked and what instruments and procedures are used. The study by Edelman, Fulton, Kuhn, and Chang (2005, this issue) had similar findings, using many of the same instruments and procedures. These findings indicate that there is no single, quick, and easy way to measure quality of life in these residents, whether for research, staff training, quality improvement, or quality monitoring purposes. Both research teams conclude that different instruments and procedures are probably measuring different perspectives and realities and that a combination of approaches is needed to get a full picture of residents' quality of life.

The findings from these two studies and the comprehensive review of DCM by Brooker (2005, this issue) add greatly to current knowledge about

measuring quality of life in people with dementia. More research is needed. In the meantime, it should be noted that people with quite advanced dementia were able to respond consistently to quality-of-life questions in both the CS-LTC Dementia Care and Edelman studies. We believe resident responses are very important and that resident interviews should be included in future research and quality-improvement initiatives.

For the CS-LTC Dementia Care study, the research team and liaison panel identified six areas of care for special attention: depression, behavioral symptoms, pain, food and fluid intake, activity involvement, and mobility. The way the research team looked at these areas of care—by measuring (a) the proportion of residents who had problems in each area, (b) whether and how these problems had been assessed by facility staff, (c) how the problems were treated, (d) how staff perceived the outcomes of treatment, and (e) how they perceived their own training, knowledge, and skills in each area—was particularly appropriate and valuable for generating practice and policy implications. The study findings helped inform the selection process of the care areas to focus on first in our *Campaign for Quality in Residential Care.* More importantly, the study served as the impetus for the Alzheimer's Association to lead the Campaign that involved key stakeholders, care experts, our chapter network, and consumers in the development of dementia care practice recommendations that will serve as the basis for advocacy efforts, staff training, and consumer education.

The Alzheimer's Association asked Dr. Zimmerman and her colleagues to expand the CS-LTC Dementia Care study to include nursing homes as well as assisted living facilities because we thought findings from the two settings would be quite different. In fact, the study found surprisingly few differences across settings in resident and staff characteristics and clinical outcomes of care. This finding is important for policy purposes, for example, for the development and revision of government regulations intended to ensure that assisted living facilities and nursing homes are capable of meeting their residents' service needs.

Despite the general finding of few differences between assisted living and nursing homes, two articles in this issue identify specific differences we think are important for anyone who is trying to choose the most appropriate residential care setting for a person with dementia. One article (Sloane, Zimmerman, Gruber-Baldini, et al., 2005, this issue) points out that hospitalization rates were higher for residents with mild dementia in assisted living versus nursing homes; the researchers suggest that assisted living facilities may have more difficulty than nursing homes taking care of a person with dementia who has substantial and/or unstable medical or nursing needs.

A second article (Port et al., 2005, this issue) points out that families of assisted living residents with dementia had higher self-reported burden than families of nursing home residents with dementia. The researchers note that assisted living facilities generally offer greater independence but less physical care and protective oversight than nursing homes; they hypothesize that the higher burden may result from additional help provided by these families in order to obtain the benefits of greater independence for their relative with dementia. And further, that the additional help provided by families may account in part for the lack of significant differences in clinical outcomes for assisted living and nursing home residents.

Findings from an ethnographic study of decisions to retain or transfer residents with dementia in three assisted living facilities also show the importance of additional help provided by families (Mead, Eckert, Zimmerman, & Schumacher, 2005, this issue). Like the study by Sloane, Zimmerman, Gruber-Baldini, and colleagues (2005, this issue), this study found that discharges from assisted living facilities resulted more often from residents' non-dementia-related health crises than from any increased cognitive impairment, behavioral symptoms, or care needs. These findings help to explain the high proportion of assisted living residents who have severe cognitive and other impairments, despite facility retention and transfer policies that would seem to require that they be discharged.

The CS-LTC Dementia Care study resulted in a complex array of findings about associations between staff attitudes, staff training, care practices, and staff and resident perceptions of residents' quality of life. Some that seem important to us are:

1. The association between better resident perceptions about their own quality of life and greater staff involvement in care planning (Zimmerman, Sloane, et al., 2005, this issue);
2. The association between better nursing assistants' perceptions of residents' quality of life, the nursing assistants' positive attitudes about person-centered care, and their positive evaluations of the adequacy of their training about dementia care (Winzelberg, Williams, Preisser, Zimmerman, & Sloane, 2005, this issue); and
3. The association between staff members' confidence in their ability to provide good dementia care, positive attitudes about person-centered care, and higher self-reported job satisfaction (Zimmerman, Williams, et al., 2005, this issue).

As noted by the researchers, the cross-sectional nature of the data that underlie these and other findings from the CS-LTC Dementia Care study means that the direction of the associations is not certain, and some of the findings may be most useful for generating hypotheses for future research. The only longitudinal component of the study, which measured change in staff perceptions of residents' quality of life during a 6-month period, found less decline in quality of life for facilities that had more

staff training centered around the six areas of care and more frequent activities and staff encouragement of resident participation in activities (Zimmerman, Sloane, et al., 2005, this issue).

Many other findings from the research reported in this issue strike us as important for dementia care. These findings include:

1. The association between resident depression and behavioral symptoms, that depression was detected in only half the residents where it was present, and that nursing home residents were more likely to be treated by a mental health professional and reside in facilities that include mental health professionals in formal care planning (Gruber-Baldini et al., and Boustani et al., 2005, this issue);

2. The relatively modest level of agreement between residents and supervisors about whether the resident had pain, and the finding that one third of residents with pain were not receiving any treatment for it (Williams, Zimmerman, Sloane, & Reed, 2005, this issue);

3. The finding that residents who had meals in public dining areas (rather than in their own rooms) and residents who had meals in dining areas with more noninstitutional features were less likely to have low food and fluid intake (Reed, Zimmerman, Sloane, Williams, & Boustani, 2005, this issue);

4. The association between mobility limitations and low fluid intake (S. Williams et al., 2005, this issue);

5. The association between grooming and staff and residents' perception of the residents' quality of life (Zimmerman, Sloane, et al. 2005, this issue); and

6. The association between greater involvement of families and greater resident participation in activities (Dobbs et al., 2005, this issue).

Other readers will certainly note other findings that strike them as important for care as well as research and policy.

We hope this issue of *The Gerontologist* will stimulate future research and public and private initiatives to improve quality of care. We are grateful to Dr. Zimmerman, Dr. Sloane, the research team for the CS-LTC Dementia Care study, and the other researchers who have contributed findings from their studies to this special issue. We also are grateful to our guest editor, Dr. Richard Schulz, for his time, diligence, and insight in bringing the special issue to fruition.

The Alzheimer's Association welcomes proposals for future studies on these topics. We hope other funders also will solicit and fund such proposals. More than half of all nursing home residents and substantial proportions of assisted living residents— a million people or more at any one time—have Alzheimer's disease or other dementias. Research to improve care and outcomes for residents with these conditions is clearly important.

The Alzheimer's Association will continue to advocate for improvements in care for assisted living and nursing home residents with dementia based on the best available evidence. We appreciate the many organizations and individuals that have worked with us thus far to produce and disseminate completed guidelines and training programs. We urge others to join our ongoing efforts to develop new guidelines, revise existing guidelines as new knowledge becomes available, and disseminate existing information and training to improve quality of care.

Dementia Care Mapping: A Review of the Research Literature

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Purpose: The published literature on dementia care mapping (DCM) in improving quality of life and quality of care through practice development and research dates back to 1993. The purpose of this review of the research literature is to answer some key questions about the nature of the tool and its efficacy, to inform the ongoing revision of the tool, and to set an agenda for future research. ***Design and Methods:*** The DCM bibliographic database at the University of Bradford in the United Kingdom contains all publications known on DCM (http://www.bradford.ac.uk/acad/health/dcm). This formed the basis of the review. Texts that specifically examined the efficacy of DCM or in which DCM was used as a main measure in the evaluation or research were reviewed. ***Results:*** Thirtyfour papers were categorized into five main types: (a) cross-sectional surveys, (b) evaluations of interventions, (c) practice development evaluations, (d) multimethod evaluations, and (e) papers investigating the psychometric properties of DCM. ***Implications:*** These publications provide some evidence regarding the efficacy of DCM, issues of validity and reliability, and its use in practice and research. The need for further development and research in a number of key areas is highlighted.

Key Words: Alzheimer's disease, DCM, Well-being, Quality of life, Quality of care

Dementia Care Mapping (DCM; Bradford Dementia Group, 1997) is an observational tool that has been used in formal dementia-care settings over the past 13 years, both as an instrument for developing person-centered care practice and as a tool in quality-of-life

research. It developed from the pioneering work of the late Professor Tom Kitwood on person-centered care. In his final book, *Dementia Reconsidered,* Kitwood (1997) described DCM as "a serious attempt to take the standpoint of the person with dementia, using a combination of empathy and observational skill" (p 4). The instrument has been described fully elsewhere (Kuhn, Ortigara, & Kasayka, 2000). In brief, an observer (mapper) tracks 5 people with dementia (participants) continuously over a representative time period (e.g., 6 hr during the waking day). Mapping takes place in communal areas of care facilities. After each 5-min period (a time frame), two types of codes are used to record what has happened to each individual. The behavioral category code (BCC) describes 1 of 24 different domains of participant behavior that has occurred. BCCs are subdivided into those behaviors that are thought to have high potential for well-being (Type 1) and those with low potential (Type 2). The mapper also makes a decision for each time frame, based on behavioral indicators, about the relative state of ill-being or well-being experienced by the person with dementia, called a well- or ill-being value (WIB). This is expressed on a 6-point scale ranging from extreme ill-being to extreme well-being. WIB values can be averaged to arrive at a WIB score. This provides an index of relative well-being for a particular time period for an individual or a group.

Personal detractions (PDs) and Positive events (PEs) are recorded whenever they occur. Personal detractions are staff behaviors that have the potential to undermine the personhood of those with dementia (Kitwood, 1997). These are described and coded according to type and severity. Positive events—those that enhance personhood—also are recorded by the mapper, but these are not coded in a systematic manner.

DCM is grounded in the theoretical perspective of a person-centered approach to dementia care. Person-centered care values all people regardless of age and health status, is individualized, emphasizes the perspective of the person with dementia, and stresses the importance of relationships (Brooker, 2004). Within Kitwood's writing is the assumption that, for people with dementia, well-being is a direct result of the quality

of relationships they enjoy with those around them. The interdependency of the quality of the care environment to the relative quality of life experienced by people with dementia is central to person-centered care practice. In placing DCM in the taxonomy of measures of quality of life and quality of care, DCM attempts to measure elements of both. In its BCCs and WIBs, DCM measures relative well-being, affect, engagement, and occupation, which are important elements of quality of life. Through PDs and PEs, DCM records the quality-of-care practice as it promotes or undermines the person-hood of those being mapped.

The method and coding system were originally developed through ethological observations of many hours in nursing homes, hospital facilities, and day care facilities in the United Kingdom (Kitwood & Bredin, 1994). It was designed primarily as a tool to develop person-centered care practice over time with data being fed back to care teams who could then use it to improve their practice. The original development work is not available in the public domain. DCM has been criticized for this (Adams, 1996). Also, many of the basic psychometric tests expected in the development of such a complex tool were not published.

Despite this, DCM has grown in popularity over the years. Many practitioners have used these codes successfully in many different situations and continue to do so. The reasons for this have not been systematically investigated. In part, it may be because DCM provides a vehicle for those wishing to systematically move dementia care from primarily a custodial and task-focused model into one that respects people with dementia as human beings. There are very few other tools that purport to do this or that have been shown to be effective in this endeavor in the field of dementia care.

DCM certification is only available through licensed trainers who undergo rigorous preparation for their role and use standardized training methods prepared by the University of Bradford. The basic training is a 3-day course, with further options of advanced training and evaluator status also available. DCM training is currently available in the United Kingdom, United States, Germany, Denmark, Australia, Switzerland, and Japan.

DCM has been through a number of changes since its inception. Until 1997, DCM 6th edition was used. In 1997, DCM was revised based on feedback from practitioners resulting in the 7th edition (Bradford Dementia Group, 1997). The changes were made, in part, to clarify terminology (e.g., care values became well- or ill-being values); there was an increase in the number of BCCs, from 17 to 24, and PEs were formally recorded as part of the DCM evaluation. There were, however, no published papers demonstrating the relationship between scores on the 6th and 7th editions of DCM. During the past 3 years, various international working groups and field trials have made suggestions for revisions to DCM 7. DCM 8 will be launched in late 2005 in the United Kingdom.

Beavis, Simpson, and Graham (2002) reviewed literature on DCM from 1992 until June 2001 and identified nine papers that met their inclusion criteria.

There have been important papers published since this time, and, using similar inclusion criteria (discussed below), the current review identified 34 papers. This review aims to clarify what is known about the DCM tool and to inform the direction of DCM 8 and future research.

Design and Methods

The international DCM network led by the University of Bradford maintains a DCM bibliographic database that contains all known publications on DCM (http://www.bradford.ac.uk/acad/health/dcm). This database formed the basis of this review. It includes refereed and nonrefereed journal articles, book chapters, theses, and non-English language texts. It is updated by the Bradford Dementia Group with annual bibliographic searches on Medline, Cinahl, and Psychinfo using the terms "DCM" and "dementia care mapping" as well as personal correspondence from practitioners and researchers.

I included articles that specifically examined the efficacy of DCM or in which DCM was a main measure in evaluation or research. There were no exclusion criteria based on quality of scientific design. Articles that were purely descriptive were excluded, as were dissertations. There are many additional articles and publications that describe aspects of DCM and its use. Some of these will be referred to in the discussion. The review includes articles published between 1993 and March 2005.

I assigned each article to one of five categories according to its basic purpose in using DCM. I developed tables that summarize key parameters pertinent to this review: (a) settings and size; (b) aims of study as set out by the authors; (c) length of time mapped; (d) sample selection and characteristics; (e) study design; (f) version of DCM used; (g) interrater reliability; (h) DCM outcomes, (i) statistical tests; and (j) level of significance. (The full tables summarizing each article can be downloaded from the Web site previously mentioned or are available on request from the author.)

Results

Thirty-four articles met the inclusion criteria. They were divided into five main types.

1. Cross-Sectional Surveys

In 11 articles, DCM was used in a number of different facilities, and the results either compared or pooled. Some of these presented baseline data for intended further studies (Wilkinson, 1993; Williams & Rees, 1997; Younger & Martin, 2000) whereas others had the explicit aim of surveying quality of care or quality of life (Ballard et al., 2001; Innes & Surr, 2001; Kuhn, Kasayka, & Lechner, 2002; Perrin, 1997). An additional 4 articles used DCM to investigate the relationship between participants' characteristics and well-being and activity (Chung, 2004; Kuhn, Edelman,

& Fultom, 2005; Kuhn, Fulton, & Edelman, 2004; Potkins et al., 2003).

Seven of these articles presented data from U.K. long-term facilities (Ballard et al., 2001; Innes & Surr, 2001; Perrin, 1997; Potkins et al., 2003; Wilkinson, 1993; Williams & Rees, 1997; Younger & Martin, 2000). Three were U.S. studies examining assisted living facilities and day care facilities (Kuhn et al., 2002; Kuhn, Edelman, & Fulton, 2005; Kuhn, Fulton, & Edelman, 2004), and 1 was from Hong Kong (Chung, 2004). They ranged in size from 30 people in 6 facilities surveyed by Wilkinson (1993) to the largest study by Ballard and colleagues (2001), who surveyed 218 people in 17 facilities; the average study size was 110 people in 8 facilities. All mapped for around 6 hr, except for Williams and Rees (1997) and Younger and Martin (2000), who mapped for 12 hr. DCM 6 was used by Wilkinson (1993), Perrin (1997), and Williams and Rees (1997).

2. Evaluation of Intervention

There were 10 articles in which DCM was used to evaluate the impact of various interventions on the lives of people with dementia. Bredin, Kitwood, and Wattis (1995) first used DCM to evaluate the impact of merging two wards. It has been used to evaluate a number of nonpharmacological therapeutic interventions, such as group reminiscence (Brooker & Duce, 2000), aromatherapy (Ballard, O'Brien, Reichelt, & Perry, 2002), sensory stimulation groups (Maguire & Gosling, 2003), intergenerational programs (Jarrott & Bruno, 2003), and horticultural therapy (Gigliotti, Jarrott, & Yorgason, 2004). It also has been used as part of the evaluation of larger scale changes in therapeutic regimen, for example outdoor activities (Brooker, 2001), person-centered care training (Lintern, Woods, & Phair, 2000a), a liaison psychiatry service (Ballard, Powell, et al., 2002), and a double-blind, placebo-controlled, neuroleptic discontinuation study (Ballard et al., 2004).

Length of time for which mapping occurred was much more varied with the shortest time being 30 min (Maguire & Gosling, 2003) to the longest at 5 days per participant (Jarrott & Bruno, 2003). Studies ranged in size from the smallest, $n = 14$ (Gigliotti et al., 2004), to the largest, $n = 82$ (Ballard et al., 2004).

All evaluations were a within-subjects design, apart from Jarrott and Bruno (2003), who compared two groups. Control groups were used in just over half the studies (Ballard, O'Brien, et al., 2002; Ballard, Powell, et al., 2002; Ballard et al., 2004; Brooker, 2001; Brooker & Duce, 2000; Gigolotti et al., 2004; Jarrott & Bruno). Demonstrable changes in DCM scores were shown in all studies with the exceptions of Lintern and colleagues (2000a); Ballard, Powell, and colleagues; and Ballard and colleagues. Statistically significant changes in DCM scores were demonstrated in Bredin and colleagues (1995); Brooker and Duce; Brooker (2001); Ballard, O'Brien, and colleagues; Jarrott and Bruno; and Gigliotti and colleagues.

3. Evaluation of DCM in Practice Development

Six articles investigated the ability of DCM to develop practice over time by means of repeated evaluations. In these reports DCM was used in a developmental process or in a continuous quality-improvement cycle with the explicit goal of using DCM data to change care practice. Barnett (1995); Brooker, Foster, Banner, Payne, and Jackson (1998), and Martin and Younger (2001) report results across a number of facilities, whereas Lintern, Woods and Phair (2000b); Martin & Younger (2000), and Wylie, Madjar, & Walton (2002) report results from single facilities. In the largest of these studies, Brooker and colleagues reported DCM across nine facilities for three annual cycles; the smallest of these was Martin and Younger (2000). DCM 6 was used by Barnett; Lintern and colleagues (2000a), and Brooker and colleagues. All of the studies showed demonstrable changes in DCM scores over time. Brooker and colleagues was the only study to use statistical analysis to demonstrate the significance of change over time.

4. MultiMethod Qualitative Evaluations

Three articles reported using DCM as part of a multimethod evaluation of a single facility or service (Barnett, 2000; Parker, 1999; Pritchard & Dewing, 2001). All these articles were qualitative evaluations and used DCM in this frame.

5. Investigations of Psychometric Properties

Four studies looked directly at some of the psychometric properties of DCM. Fossey, Lee, and Ballard (2002) examined internal consistency, test–retest and concurrent validity, and shortened mapping time in a U.K. long-term population of 2 cohorts of 123 and 54, respectively. The 2 cohorts were chosen to increase the variance in dependency and agitation. All were mapped for 6 hr on each occasion, 24 mapped 1 week apart, and 30 mapped between 2 and 4 weeks apart. Test–retest reliability was established for both cohorts. Internal consistency was demonstrated between the main parameters. A correlation was found between key parameters in the hour prior to lunch and the total 6-hr map.

Edelman, Fulton, and Kuhn, (2004) compared five dementia-specific quality-of-life measures, including DCM, in 54 people with dementia in 3 U.S. day-care facilities. WIB scores did not correlate with quality-of-life interviews but did correlate with proxy measures. WIB scores did not correlate with Mini-Mental State Examination (MMSE) scores but they did with the number of dependent activities of daily living (ADLs). In a second study on 166 people with dementia in 8 different facilities, Edelman, Kuhn, and Fulton (2004) further assessed the relationship between DCM and MMSE scores, number of dependent ADLs, depressive symptoms, and facility type. Low WIB scores and higher percentages of sleep correlated with low MMSE scores and higher dependency. WIB scores were

lower in dementia specific nursing homes than assisted living facilities and day care. There was not a significant relationship between DCM scores and depressive symptoms.

Thornton, Hatton, and Tatham (2004) assessed interrater reliability in routine mapping on 20 participants. They also compared BCCs to actual amount of time spent in different behaviors and looked at the relationship between dependency and WIB scores in 64 patients in a U.K. long-stay and day-care facility. They found that interrater reliability in routine maps was less than 50% for 12 codes. They also demonstrated that DCM gives lower indication of passive and withdrawn behaviors than continuous time sampling. Correlations between dependency and WIB score also were demonstrated.

DCM Data Across Studies

Despite the variety of studies, there is consistency of what they report in terms of DCM data. In long-term care, BCC codes A (social interaction), B (watching), and F (eating and drinking) appear as the most frequent codes almost without exception. Codes K (walking) and N (sleeping) appear as the next most frequently cited. In facilities with lower WIB scores, C (withdrawn) and W (repetitive self-stimulation) appear in the top five (Chung, 2004; Innes & Surr, 2001; Perrin, 1997). In facilities with higher WIB scores, codes E (creative activity), J (exercise), and M (engaging with media such as books, TV) appear more frequently (Brooker et al., 1998; Kuhn et al., 2002; Martin & Younger, 2001). Taking the group WIB scores across the studies as a whole ($n = 39$, excluding the less well-described studies) these provided an average (mean) group WIB of 0.9 ($SD = 0.92$) for long-term care. Group WIB scores from long-term care facilities ranged between −0.32 (Ballard et al., 2001) to 1.5 (Innes & Surr, 2001).

Generally, a greater diversity of BCCs and higher WIB scores are reported in day-care facilities (Barnett, 2000; Brooker et al., 1998; Kuhn et al., 2004; Martin & Younger, 2001; Williams & Rees 1997) with BCC codes M (media), G (games), L (work-like activity) and I (intellectual), J (physical exercise), E (creative expression), and H (handicrafts) appearing in the top five reported codes. Of the eight day-care group WIB scores reported, the mean is 1.94 (range = 1.17 to 2.79, $SD = 0.47$). WIB scores and diversity of activity both increase during periods of therapeutic activity (Brooker & Duce, 2000; Gigliotti et al., 2004; Jarrott & Bruno, 2003; Maguire & Gosling, 2003; Pritchard & Dewing, 2001; Wilkinson, 1993).

There is less data available for assisted-living facilities, the only report being Kuhn and colleagues (2002). The spread of WIB scores and the frequency of BCCs were similar to those reported for nursing home facilities. Lower scores, less diversity of activity, and a greater occurrence of personal detractions occurred in the smaller dementia-specific facilities rather than in larger mixed facilities, although this could have been confounded with greater dependency in the smaller facilities.

Many published DCM evaluations do not report PDs. A number suggest that the highest level of PDs occur in those facilities with the lowest WIB scores (Brooker et al., 1998; Innes & Surr, 2001; Kuhn et al., 2002; Williams & Rees, 1997). Most PDs reported fall in the mild to moderate category. Innes and Surr were the only authors to report positive events. Nineteen of the studies reported interrater reliability data which ranged from 0.7 to 1.0, most reporting concordance coefficients of 0.8.

Implications

These studies can help to answer, at least in part, some common questions about DCM. In addition to this, issues are highlighted that should be taken forward in the development of DCM.

Does DCM Measure Quality of Care and/or Quality of Life?

In terms of concurrent validity with other measures there is some evidence that DCM is related to indicators of quality of care. Bredin and colleagues (1995) reported a relationship between a decrease in DCM scores and an increase in pressure sores. Brooker and colleagues (1998) reported a clustering of high WIB scores occurring in facilities where other quality audit tools demonstrated better quality of care.

There is some evidence of concurrent validity of WIB scores with proxy quality-of-life measures. Fossey and colleagues (2002) demonstrated a significant correlation between WIB scores and the Blau (1977) proxy measure of quality of life. Edelman and colleagues (2004) demonstrated a moderately significant correlation between WIB scores and two staff proxy measures of quality of life—the Quality of Life AD–Staff (Logsdon, Gibbons, McCurry, & Teri, 2000) and the Alzheimer's Disease-Related Quality of Life (ADRQL; Rabins, Kasper, Kleinman, Black, & Patrick, 1999) in adult day care. This study did not demonstrate a correlation between any of these measures compared to direct quality-of-life interviews with a less cognitively impaired subgroup. In his multimethod study, Parker (1999) noted that during interviews, people with dementia rated their quality of life as better than their DCM scores would suggest.

Data from a larger, as yet unpublished, study (Edelman, Kuhn, Fulton, Kasayka, & Lechner, 2002) also compared DCM results with another observational measure—the Affect Rating Scale (Lawton, 1997). On the Affect Rating Scale, positive WIBs correlated with positive affect and negative WIB scores with negative affect. Brooker and colleagues (1998) also demonstrated a significant correlation between WIB score and level of observed engagement (McFayden, 1984) on a small sample of 10 participants.

DCM measures something similar to proxy measures and other observation measures. DCM is somewhat different from other quality-of-life and quality-of-care measures in that it attempts to measure elements of

both. In training to use DCM, mappers are explicitly taught to increase their empathy for the viewpoint of the person with dementia and to use this during their coding decisions.

Can Different Mappers Use DCM Reliably?

When many different mappers are engaged in mapping at different points in time, drifts in coding can have a significant impact on results (Thornton et al., 2004) unless systematic checking is in place to prevent this. It is perfectly possible to achieve acceptable interrater reliability as many of the studies here demonstrate. Surr and Bonde-Nielsen (2003) outline the various ways in which reliability can be achieved in routine mapping. Although interrater reliability can be demonstrated within studies—and should always be so where more than a single mapper has been used—it cannot be assumed when comparing one study to another. This is a major challenge for those providing DCM training. One of the main ways of achieving interrater reliability in practice is for all mappers to have regular checks with a "gold standard mapper." Provisions need to be made to make the status of a gold standard mapper more formalized, possibly through advanced DCM training. This status could be accredited by regular web-based or video role-play materials that mappers have to code correctly to maintain their status.

In terms of the development of DCM 8, efforts should be made to decrease ambiguity in the codes and to eliminate any unnecessary complexity from the rules. Thornton and colleagues (2004) and work currently being undertaken in Germany (Ruesing, 2003) have helped clarify the most problematic codes. There are no published data on the interrater reliability of PD and PE recordings. This also should be incorporated in DCM 8.

Only Fossey and colleagues (2002) looked at test–retest reliability. The best correlation was between percentage of +3 and +5, followed by overall WIB score. Significance was more moderate for type of BCC but still at an acceptable level. This finding requires replication.

Does DCM Show Representative Reliability Across All People With Dementia?

There is evidence to suggest that level of dependency is correlated with DCM scores, specifically that low WIB scores are associated with high dependency levels. This has been demonstrated statistically on three different continents (Brooker et al., 1998; Chung, 2004; Edelman et al., 2004; Kuhn et al., 2004; Thornton et al., 2004) using three different measures of dependency.

On the other hand, Younger and Martin (2000) found the highest scores in their study occurred in the facility that had the most dependent participants. Edelman and colleagues (2004), Jarrott and Bruno (2003), and Gigliotti and colleagues (2004) demonstrated no correlation between level of cognitive impairment and WIB score.

The correlations between low WIB scores and high

dependency may of course be related to a third factor of poorer quality of psychosocial care for people with dementia who have high dependency needs. In support of this, Brooker and colleagues (1998) found that the correlation between dependency and WIB score disappeared after three successive cycles of DCM. The authors believed that, by this stage, ways of supporting well-being of participants who were highly dependent had been better established.

It is also not clear whether there are particular features that are more prevalent in higher dependency groups that might either make a subset more difficult to engage with and thus more difficult for them to achieve higher DCM scores. For example, Potkins and colleagues (2003) demonstrated that language dysfunction was associated with poorer BCC distribution regardless of level of cognitive impairment.

The evidence that dependency level skews DCM results is strong enough to suggest that a measure of dependency should be routinely taken alongside DCM evaluations so that the results can be scrutinized for this relationship. One of the problems with doing this is agreeing on a particular measure of dependency. The Clifton Assessment Procedures for the Elderly measure (CAPE; Pattie & Gilleard, 1979) has been used most often but is difficult to access and not culturally appropriate outside the United Kingdom. A standard measure of dependency to be used alongside DCM needs to be agreed upon.

Does DCM Change Care Practice?

In 2001, an international "think tank" of DCM practitioners came together to review their collective experience on DCM (Brooker & Rogers, 2001). Their conclusions from practice were that DCM, used within an organizational framework that supported person-centered care, could improve levels of well-being, increase the diversity of occupation, and decrease the incidence of personal detractions. The published developmental evaluations reviewed here supports this assertion both for larger scale quality-assurance initiatives (Brooker et al., 1998, Martin & Younger, 2001) and more in-depth developments in single establishments (Lintern et al., 2000b; Martin & Younger, 2000; Wylie et al., 2002). The face validity of DCM for practitioners appears high in formal evaluations (Brooker et al.; Younger & Martin, 2000) and in the large numbers of people undertaking DCM training.

DCM has been used as a tool for practice development by many people and organizations. The mix of papers in this review cannot be taken as a reflection of the way in which DCM is used generally. By the nature of their work, those in practice development are less likely to publish than those engaged in research. The research issue for whether DCM changes care practice is to clarify the way in which DCM is used and the organizational setting conditions necessary to maximize impact.

A difficult issue, in terms of validity for practice development, is whether using DCM in a repeated cycle

of evaluations actually *improves* quality of life for people with dementia. A problem with all of the studies outlined above is that their only measure of improvement was DCM. In other words, DCM served as both the intervention and the outcome measure. Without a longitudinal controlled study of DCM as a tool for practice development, which utilizes other quality of life measures as the main outcome, it cannot be said categorically that DCM improves quality of life. There are many practitioners who believe that DCM does have a positive impact when used within certain setting conditions (Brooker & Rogers, 2001). In the context of working in a field where tools for practice development are not common, DCM is a tool that practitioners want to use.

Is DCM a Suitable Tool for Research?

DCM was not designed to be a research tool, and investigations into its reliability and validity are only just beginning to appear. Acceptable interrater reliability is achievable, and concurrent validity with other proxy measures of quality of life has been demonstrated. Fossey and colleagues (2002) demonstrated internal consistency and test–retest reliability. These findings require replication, and the issue of the impact of dependency and diagnosis on scores needs to be determined, as does the impact of care regimen. Further research into its psychometric properties continues, and more studies are expected. Careful consideration should be given in deciding whether DCM is fit for purpose given the specific topic under investigation.

DCM has been used in cross-sectional surveys, evaluations of interventions, and multimethod qualitative evaluations by a number of researchers. In terms of cross-sectional surveys, there are tools that may be more suited to this task that do not have the attendant time-consuming problems and specialist training associated with DCM (Edelman et al., 2004). Whether they would be better tools for the purpose of answering the specific research questions is debatable.

From the studies presented here, DCM seems to be suited to smaller scale within-subjects or group comparison intervention evaluations, given that it appears to demonstrate discrimination on a variety of interventions. In multimethod qualitative designs, DCM appears to enrich the data derived from proxy and service-user interviews and focus groups. DCM provides an opportunity to represent a reflection on what could be the viewpoint of service users who are unable to participate fully in interviews.

What is clear is that BCCs do not measure real-time estimates of different types of behavior (Thornton et al., 2004). Because of the rules of coding in DCM, it will underestimate the occurrence of socially passive and withdrawn behavior compared to data collected with continuous time sampling. Researchers interested in looking at withdrawn and passive behavior might be better advised to use another tool. It is worthy of note, however, that despite this, three studies (Ballard, O'Brien et al., 2002; Gigliotti et al., 2004; Potkins

et al., 2003) found DCM discriminated between groups on social withdrawal in their evaluations.

There are a number of modifications to DCM that might prove useful when using DCM in research. A current U.S.-led project is considering whether some of the operational rules within DCM for selecting specific BCC and WIBs should be changed for the purposes of research evaluations. A number of studies reviewed that presented group-level data have collapsed the number of BCCs into a number of supracategories (Chung, 2004; Gigliotti et al., 2004; Kuhn et al., 2004). It may be that streamlining DCM further by using time sampling could provide a more useful research alternative as has already been tried by McKee, Houston, and Barnes (2002). Further research is needed to clarify how streamlined versions relate to the full tool and whether the same degree of training would be necessary to use them.

What Do the Scores Mean in Terms of Benchmarking?

The table on how to interpret DCM data in the DCM manual (Bradford Dementia Group, 1997) is not based on published data. Evidence from this review presents a range of group WIB scores against which to benchmark, suggesting that scores are generally higher in day care than long-stay care. How much this is confounded by the different dependency levels is unclear. Work is currently underway to develop an international database of DCM results to which all international strategic DCM partners would have access. The database should include participant and facilities factors that could be used in stratified analyses, correlational studies, and as adjustment factors. The quality of DCM data in the international database could be safeguarded by only accepting data that has been verified by a gold-standard mapper.

What Is a Significant Change in Scores?

Published studies that have looked at change through developmental evaluation report group WIB changes in the range of 0.5. A study by Brooker and colleagues (1998) was the only developmental evaluation to present a statistical analysis of the results where changes of 0.1 to 0.5 were significant at the 0.03 level over 3 data points, and changes at 0.7 and 0.9 were significant at the 0.005 and 0.001 level, respectively, between 2 data points. Intervention studies (Brooker & Duce, 2000; Brooker, 2001; Gigliotti et al, 2004; Jarrott & Bruno, 2003) report differences in the range of 0.4 to 1.1, which were all statistically significant. Changes in individual WIB scores, WIB value profiles, and BCC profiles are more variable. Further research is needed to clarify what constitutes a clinically significant change.

How Long Should a Map Be?

Six hr is the current guidance in DCM training, but there is no empirical evidence to verify the representativeness of this time period. Most of the studies here have

mapped for 6 hr, although those using DCM for practice-development purposes mapped for much longer (Brooker et al., 1998; Martin & Younger, 2001; Williams & Rees; Wylie et al., 2002). It also is evident from practice that useful insights can be gained from mapping for just a couple of hours (Heller, 2004). Length of maps will depend, in part, on the reason for mapping, but there is a drive to spend the least amount of time possible collecting data. Fossey and colleagues (2002) found a statistically significant correlation between the hour prior to lunch and a 6-hr map on all their key indicators at the group level. It is likely that there would be a great deal more variation on an individual level. An un-published U.S study (Douglass & Johnson, 2002) mapped 18 residents during a 6-day period for periods of 2, 4, 6, and 8 hr in a continuing care retirement community. Acceptable levels of interrater reliability were demonstrated in maps of more than 4 hr in duration. This important issue requires further research.

Conclusions

These studies report evidence that DCM has a role in practice development and research within the broad aim of improving the quality of the lived experience for people with dementia. Priority should be given to a controlled longitudinal study to evaluate fully the impact of DCM in improving quality of life through practice development. A large international database on DCM results would help clarify the relationship between DCM results, dependency, diagnostic group, and facility characteristics. Steps need to be taken through the development of the method, training, and accreditation to ensure reliability. Further research would help clarify the clinical significance of change in scores, the length of mapping, and amendments to the method when it is used as a research tool.

The published work on DCM is of variable quality but is growing in strength. DCM's advantages are that it is standardized, quality controlled, international, responsive to change, multidisciplinary, and has an increasing research base. DCM provides a shared language and focus across professional disciplines, care staff, and management teams. It is seen as a valid measure by frontline staff as well as those responsible for managing and commissioning care. It also provides a shared language between practitioners and researchers. DCM holds a unique position in relation to quality of life in dementia care, being both an evaluative instrument and as a vehicle for practice development in person-centered care. Many of the intervention evaluations cited above have been undertaken because DCM has given practitioners a way of trying to evaluate their practice. Maintaining a dialogue between the worlds of research and practice in health and social care is a major challenge. DCM provides an opportunity to do this.

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The Association of Neuropsychiatric Symptoms and Environment With Quality of Life in Assisted Living Residents With Dementia

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Purpose: We conducted this study to determine whether neuropsychiatric symptoms and environmental characteristics are associated with quality of life in assisted living residents with dementia. **Design and Methods:** We used a cross-sectional study of 134 residents from 22 facilities and employed the Alzheimer's Disease-Related Quality of Life Scale and the Neuropsychiatric Inventory. A scale was developed to capture the homelike climate of each facility. Linear regression analyses were used to estimate the relationship of neuropsychiatric symptoms and homelike climate with quality of life, controlling for sociodemographics, cognition, functional dependence, and physical health. Exploratory analyses and graphical techniques were employed to test for environmental-level moderating effects. **Results:** Agitation, depression, apathy, and irritability were significant predictors of quality of life, explaining 29% of the variance. Neither facility size nor homelike environment was significantly associated with quality of life in univariate analyses. Size of facility moderated the relationship between agitation and quality of life. **Implications:** Neuropsychiatric symptoms impair quality of life in residents with dementia. Further re-

search should investigate the role of other environmental aspects.

Key Words: Quality of life, Dementia, Mental health, Environment

Assisted living has been growing rapidly as a residential long-term care option over the last decade (AARP, 2002) and is increasingly utilized by older adults who can no longer live independently (National Center for Assisted Living [NCAL], 2001). Presently, there is no federal regulatory oversight of assisted living, though most states have policies in place or planned (Mollica, 2001). Although definitions vary, assisted living is generally conceptualized as a residential setting primarily serving elders that provides or coordinates personal care, 24-hour supervision, scheduled and unscheduled assistance, activities, and meals (Hawes, Phillips, & Rose, 2000; NCAL). In contrast to other care settings, assisted living has an expressed mission, which is to maximize quality of life and the ability to "age in place" (Bernard, Zimmerman, & Eckert, 2001; NCAL) by providing a supportive, homelike environment (Hawes et al.).

Dementia, a major cause of disability, is extremely common in assisted living. Estimates of the prevalence of dementia and cognitive impairment in assisted living vary depending on assessment methods. Indirect assessments, which include medical chart reviews and caregiver interviews, have suggested rates that range from 18% to 70% (Hendrie, 1998). Direct assessments, involving in-person measurement of cognitive functioning, suggest rates of cognitive impairment ranging from 45% to 63% (Morgan, Gruber-Baldini, & Magaziner, 2001). In a recent study based on an extensive in-person clinical examination, we found that

67.7% of 198 randomly selected assisted living residents met dementia criteria, and 74.3% had clinically significant cognitive impairment (Rosenblatt et al., 2004). Given the substantial number of affected residents, the examination of factors related to quality of life in this subgroup will be important in determining the efficacy of current health care practices and policies in assisted living.

The conceptualization and measurement of quality of life, especially in the context of dementia has been the focus of much debate (Rabins & Kasper, 1997). Quality of life is a complex, multidimensional construct (Whitehouse & Rabins, 1992) that has been defined and interpreted in various ways. Traditional definitions of quality of life have included a subjective component (Lawton, 1991). That is, the individual has the opportunity to rate his or her own quality of life. Dementia presents a unique problem in that some affected individuals are unable to accurately reflect on and/or express their internal states.

There are a number of measurement techniques researchers have employed to measure quality of life in individuals with dementia (Ready & Ott, 2003). Some measures focus on patient self-assessments (Brod, Stewart, Sands, & Walton, 1999; Selai, Trimble, Rossor, & Harvey, 2001; Logsdon, Gibbons, McCurry, & Teri, 2002). Preliminary investigations of these scales demonstrate good reliability and some validity (Brod et al.; Selai et al.; Logsdon et al.), although the study samples have been limited to individuals with mild to moderate dementia. Lawton (1994) suggested the importance of developing measures that include externally observable elements. In this vein, direct observational techniques have been developed in which ratings in certain quality-of-life domains are based on a number of operationalized behavioral criteria during set time intervals of observation (Kitwood & Bredin, 1997; Lawton, Van Haitsma, & Klapper, 1996). These techniques also have shown good internal consistency reliability, have correlated with informant ratings, and have been useful for those with more severe dementia (Lawton et al.). Proxy ratings, a third type of assessment strategy, typically use caregiver respondents to assess an individual's quality of life by having respondents rate items based on observable behaviors (Albert et al., 1996; Rabins, Kasper, Kleinman, Black, & Patrick, 1999). These also have shown internal consistency reliability (Black, Rabins, & Kasper, 2002), inter-rater reliability, and some have shown moderate degrees of validity when compared to direct patient interview on certain behavioral indicators of quality of life (Albert et al.). For the two latter approaches, a potential limitation is the lack of direct patient input in measuring a concept that is intrinsically subjective. The tradeoff is that these measures may be more appropriate for individuals with greater degrees of cognitive impairment (Ready & Ott).

In the current study, we have used a proxy-rated, multidimensional measure specifically designed for use in dementia—the Alzheimer's Disease-Related Quality of Life Scale (ADRQL; Black et al., 2002). This scale consists of five domains: social interactions, awareness of self, feelings and mood, enjoyment of activities, and response to surroundings (Rabins et al., 1999). Because the ADRQL was developed as a dementia-specific tool, the questionnaire was designed to include items that would be minimally influenced by the cognitive and functional declines that characterize dementia. This approach allowed for the possibility of high quality of life even in later stages of disease. We chose this scale in anticipation of a wide range in severity of cognitive impairment in the assisted living setting.

The most common forms of dementia are progressive and inexorable. Mitigation of behavioral problems and optimization of the environment are the primary treatment modalities, and quality of life, however it is defined, is perhaps the most important outcome measure. Therefore, we set out to discover whether quality of life among assisted living residents with dementia is correlated with neuropsychiatric symptoms and the congenial, homelike qualities of the environment in which they live.

Several investigations have focused on the factors related to quality of life in long-term care residents with dementia. In one study, low quality of life was associated with worse orientation, increased functional dependence, depressive symptoms, and treatment with anxiolytics (Gonzalez-Salvador et al., 2000). Significant associations between reduced quality of life and functional dependence but not neuropsychiatric symptoms were found in another study that utilized an observational method (Ballard et al., 2001). Finally, in an observational study of assisted living residents with dementia, lower quality of life was associated with assisted living residents living in smaller, dementia-specific facilities compared to larger non-dementia-specific sites (Kuhn, Kasayka, & Lechner, 2002). Most of these studies did not have access to detailed neuropsychiatric assessments or randomly selected samples.

By definition, the homelike and supportive nature of the assisted living environment is itself an intervention meant to enhance quality of life. Sloane, Zimmerman, and Walsh (2001) suggested the importance of seven aspects of the physical environment: safety and security, resident orientation, stimulation without stress, privacy and personal control, facilitation of social interaction, continuity with the past, and cleanliness. Environmental factors may mitigate the negative effects of neuropsychiatric symptoms, such as agitation, by facilitating strong individualized relationships between caregivers and residents that lead to resolution of symptoms (Cohen-Mansfield & Werner, 1998). While the theorized relationship between assisted living facility factors and quality of life has face validity, there is little research to show the positive effects of environmental aspects such as "homelikeness" on resident quality of life (Sloane et al.).

In the current study we hypothesized that the presence of neuropsychiatric symptoms and the characteristics of the environment would be two major correlates of quality of life in assisted living residents with dementia. Specifically, we predicted that delusions, hallucinations, agitation, dysphoria or depression, anxiety, euphoria, apathy, disinhibition,

irritability, aberrant motor behavior, sleep, and appetite (Cummings, 1997) would be associated with lower quality of life. We further hypothesized that a smaller, more homelike setting would be associated with higher quality of life.

A second aim of these analyses was to determine whether environmental characteristics, specifically the homelike quality or size of facility, could moderate any relationship between neuropsychiatric symptoms and low quality of life. Therefore, we hypothesized that residents with neuropsychiatric symptoms living in smaller, more homelike facilities would have a higher quality of life than those with neuropsychiatric symptoms in other environments.

Methods

Study Overview

The data are derived from the Maryland Assisted Living Study, an ongoing epidemiological study of dementia and other psychiatric disturbances in assisted living. The methods from the cross-sectional phase of the study are described in detail elsewhere (Rosenblatt et al., 2004). In brief, 22 assisted living facilities stratified by size were chosen at random from a list of all licensed or pending license assisted living facilities within the Central Maryland region. This region included a large urban area (city of Baltimore), several suburban areas (Baltimore, Anne Arundel, Howard, Prince George's, and Montgomery counties), and two rural areas (Harford and Carroll counties). The sample consisted of 10 large facilities (16 or more beds) and 12 small facilities (15 beds or less). In large facilities, 15 residents were selected randomly from a list of occupied rooms provided by the facility director and approached to participate. All residents living in small facilities were approached to join the study.

Informed consent was obtained from all residents. For those with known or suspected cognitive impairment, consent to participate also was obtained from their legal representative or responsible family member. Participants received a comprehensive in-person clinical evaluation by a research team consisting of a geriatric psychiatrist, nurse, and psychometrist. Detailed history and information on current status were obtained from the participant, a family informant, assisted living medical records, and the facility staff. The state of Maryland requires all assisted living facilities to keep resident records that must include a preadmission assessment detailing medical and psychiatric conditions, medical orders and rehabilitation plans, the resident service plan, and an emergency data sheet (Code of Maryland Regulations [COMAR], 2004). All of the above information was reviewed at an adjudication conference for each case by a multidisciplinary panel of experts in the field of geriatrics. Diagnoses of dementia and psychiatric illness were assigned using Diagnostic and Statistical Manual of Mental Disorders: 4th Edition criteria (American Psychiatric Association [APA], 2000). The study was approved by the Johns Hopkins School of Medicine Institutional Review Board.

Participants

The original study sample consisted of 198 assisted living residents who were evaluated between February 2001 and January 2003. One hundred and fifty (75%) of these were living in large facilities. The majority of the residents were widowed (70%) and female (78%). Mean age was 85.6 years. The racial composition, which was representative of Maryland's population in this age group, was 83% Caucasian, 16% African American, and 1% other races. One hundred and thirty four (67.7%) residents met criteria for dementia, and an additional 13 (6.6%) met criteria for other types of cognitive disorders (Rosenblatt et al., 2004). This analysis focused on the 134 residents with dementia. All 22 assisted living facilities (i.e., 10 large and 12 small) were represented in the study sample.

Measures

Quality of life was assessed using the ADRQL (Rabins et al., 1999). The ADRQL was developed explicitly for use in individuals with dementia and was administered to the resident's formal caregiver (i.e., the facility staff member most involved in the resident's daily care). The scale contains 47 true or false items divided into five domains: social interaction, awareness of self, feelings and mood, enjoyment of activities, and response to surroundings. Items are rated on observations made in the last 2 weeks. The measure has demonstrated internal consistency ranging from .77 to .91 (Black et al., 2002), concurrent validity (Gonzalez-Salvador et al., 2000) and sensitivity to change over time (Lyketsos et al., 2003).

The Neuropsychiatric Inventory (NPI), also administered to the formal caregiver, was used to quantify the frequency and severity of 12 neuropsychiatric symptoms: delusions, hallucinations, agitation or aggression, dysphoria, anxiety, euphoria, apathy, disinhibition, irritability, aberrant motor behavior, sleep, and appetite and eating disorders (Cummings, 1997). This measure has good interrater and test–retest reliability and good content and concurrent validity (Cummings et al., 1994). Higher scores indicate greater frequency and/or severity of symptoms.

Functional impairment of residents was assessed using the Psychogeriatric Dependency Rating Scale–Physical Dependency Subscale (PGDRS-P; Wilkinson & Graham-White, 1980). The measure was administered to the formal caregiver and scores ranged from 0 (not functionally dependent) to 39 (severely functionally dependent). The General Medical Health Rating (GMHR) was used to assess medical comorbidity (Lyketsos et al., 1999). Scores ranged from 4 (excellent health) to 1 (poor health). Cognition was assessed globally using the Mini-Mental State Exam (MMSE; Folstein, Folstein, & McHugh, 1975). Scores ranged from 0 to 30 (higher scores indicate better cognition).

The Hopkins Homelike Environmental Rating Scale (HHERS) was developed in the Maryland Assisted Living study. This 14-item measure was designed to capture the overall homelike climate of each facility. It consists of two subscales: family-like social climate (e.g., "Facility caregivers interact socially with the residents") and homelike physical environment (e.g., "Residents' rooms are tailored to their personal taste"). Each item is rated on a 6-point Likert scale. Interrater reliability was determined across all 22 facilities by three independent raters. Intraclass correlation coefficients ranged from .47 to .93 for the 14 items, and the total score coefficient was .88. Final item ratings used in this analysis were the mean of the three scores. The two subscales were highly correlated (Pearson's $r = .85$). The total score equaled the sum of the two subscales. Internal consistency reliability for the scales items was high (Cronbach's $\alpha = .86$). Higher scores indicated a more homelike climate.

Analyses

Descriptive statistics were computed to determine the normality, mean, variance, and/or range of the variables. All NPI symptom domains and the length of stay in assisted living were significantly positively skewed. Log transformations were performed prior to statistical analyses. The ADRQL total percent score was calculated by adding all five domain scores and then deriving a total percentage score (participant's total observed score ÷ total possible score × 100). A histogram was generated to check the normality of the ADRQL distribution. The HHERS score was used both as a continuous variable and as a dichotomous variable (split at the median).

Univariate linear regression was employed to estimate the association of putative variables with quality of life. At this stage, all 12 subscale scores from the NPI, the HHERS total score, and facility size (dichotomous variable) were entered separately. Demographic variables, functional dependence, medical health, and cognitive function were examined as potential covariates.

A series of multivariate linear regression models were then computed. In Model 1, all variables found to be significant in the univariate analyses were entered into a hierarchical multivariate regression to estimate the relative independent contribution of each. Entry parameters for this model were set at $p \leq 0.05$ for a variable to be entered and $p \geq 0.10$ to be removed. In Model 2, all significant covariates and some additional demographic variables were entered into the first step of a multivariate regression model followed by the stepwise entry of the four significant neuropsychiatric symptoms in Step 2. This model was constructed so that the association between quality of life and the neuropsychiatric symptoms could be isolated after accounting for the influences of significant covariates and demographic differences.

To assess whether homelike environment and/or size of facility were likely to moderate the relationship between quality of life and the strongest independent neuropsychiatric symptoms, a series of regression models with associated graphs were examined. Interaction variables, designed to capture the moderating effects of these variables, were computed by multiplying each of the dichotomous homelike and size variables by the prominent neuropsychiatric symptom scores. These interaction variables were then added to the regression models. Scatterplots and boxplots were examined to assess whether there was evidence of patterns of interactions between the neuropsychiatric symptoms and facility environment variables on quality of life.

Results

Description of Resident Characteristics and Quality of Life

Descriptive statistics on participant demographics and the assessment variables for the study sample ($n = 134$) are reported in Table 1. Seventy-one percent of the residents were living in large assisted living facilities. The majority of residents with dementia were widowed (72.4%), Caucasian (79.9%), and female (80.6%). The racial mix was consistent with the Maryland population in this age group. The mean age was 86.1 years. The mean score for the total ADRQL was 77.8% ($SD = 13.55$), and scores ranged from 35% to 100%.

Correlates of Quality of Life

The significant correlates of ADRQL include delusions, hallucinations, agitation or aggression, dysphoria or depression, anxiety, apathy, disinhibition, irritability, and aberrant motor behavior (see Table 2). Agitation or aggression (NPI-C) was the neuropsychiatric symptom that best predicted quality of life, accounting for 19% of the variance. Apathy (NPI-G) and irritability (NPI-I) were slightly weaker predictors, estimating 17.5% and 13.2% of the variance, respectively. Homelike environment and facility size were not significant predictors of quality of life. Of the covariates, greater physical dependency (PGDRS-P), worse cognitive functioning (MMSE), and worse physical health (GMHR) were significantly associated with lower quality of life. With the exception of marital status, none of the sociodemographic variables were significantly associated. Being widowed, as opposed to being married, divorced, or never married, was significantly correlated with better quality of life.

In Table 3, Model 1, the results of a hierarchical multivariate regression analysis are displayed. Agitation or aggression, apathy, functional dependency, dysphoria or depression, marital status, irritability, and cognition were significant predictors of quality of life and collectively accounted for approximately 51% of the variance. Table 3, Model 2 presents the results of a multivariate regression model in which all significant covariates and some demographic variables were entered into the first block followed by the stepwise entry of the 4 neuropsychiatric symptoms. In Block 1, age, gender, race, marital status, physical dependency,

Table 1. Descriptive Statistics for Demographic and Assessment Variables

Variable	M	SD	Minimum	Maximum
Social demographic				
Age, years ($n = 134$)	86.1	(6.7)	65.1	104
Education, years ($n = 130$)[a]	13.5	(3.0)	4	20
Cost, months ($n = 129$)[a]	3139.53	(1463.62)	300.00	7500.00
Length of residence in assisted living, years ($n = 134$)	2.0	(1.7)	0.1	9.4
Assessment variable				
MMSE ($n = 133$)[a]	14.64	(7.67)	0	29
PGDRS-Physical ($n = 132$)[a]	14.23	(8.81)	0	34
GMHR, ($n = 134$)	2.47	(0.79)	1	4
HHERS, ($n = 134$)	56.10	(9.78)	42.67	73.33
NPI-A (delusions; $n = 134$)	1.57	(2.86)	0	12
NPI-B (hallucinations; $n = 134$)	0.45	(1.66)	0	12
NPI-C (agitation or aggression; $n = 134$)	1.47	(2.35)	0	9
NPI-D (dysphoria or depression; $n = 134$)	1.19	(2.50)	0	12
NPI-E (anxiety; $n = 134$)	1.28	(2.86)	0	12
NPI-F (euphoria; $n = 134$)	0.11	(0.66)	0	6
NPI-G (apathy; $n = 134$)	1.32	(2.97)	0	12
NPI-H (disinhibition; $n = 134$)	0.43	(1.44)	0	8
NPI-I (irritability; $n = 134$)	1.69	(2.90)	0	12
NPI-J (aberrant motor behavior, $n = 133$)[a]	1.20	(2.72)	0	12
NPI-K (sleep; $n = 133$)[a]	1.47	(3.00)	0	12
NPI-L (appetite and eating; $n = 133$)[a]	0.75	(2.17)	0	9
ADRQL ($n = 134$)	77.81	(13.55)	35	100

Notes: MMSE = Mini-Mental State Exam, PGDRS-P = Psychogeriatric Dependency Rating Scale, GMHR = General Medical Health Rating, HHERS = Hopkins Homelike Environment Rating Scale, NPI-A–L = Neuropsychiatric Inventory domains, ADRQL = Alzheimer's Disease-Related Quality of Life (total % scores).

[a]Data were not available for all 134 residents.

Table 2. Results of Univariate Regression Analyses: Significant Correlates of Quality of Life

Independent Variables	β (SE)	P	Adjusted R^2
Marital status (dichotomous)	−5.64 (2.58)	.031	.028
MMSE	0.54 (.148)	< .001	.086
PGDRS-P	−0.62 (.124)	< .001	.157
GMHR	2.95 (1.46)	.046	.023
NPI-A (delusions)	−9.74 (3.23)	.003	.057
NPI-B (hallucinations)	−13.49 (5.38)	.013	.038
NPI-C (agitation or aggression)	−17.68 (3.11)	< .001	.190
NPI-D (dysphoria or depression)	−13.01 (3.47)	< .001	.089
NPI-E (anxiety)	−8.02 (3.40)	.020	.033
NPI-G (apathy)	−14.76 (3.21)	< .001	.132
NPI-H (disnhibition)	−14.21 (5.43)	.010	.042
NPI-I (irritability)	−15.54 (2.88)	< .001	.175
NPI-J (aberrant motor behavior)	−13.67 (3.29)	< .001	.109
HHERS total score[a]	0.12 (2.59)	.334	.000
HHERS median split (dichotomous)[a]	1.96 (2.46)	.427	−.003
Size of facility (dichotomous)[a]	0.77 (2.59)	.767	−.007

Notes: MMSE = Mini-Mental State Exam, PGDRS-P = Psychogeriatric Dependency Rating Scale, GMHR = General Medical Health Rating, NPI-A-L = Neuropsychiatric Inventory domains, HHERS = Hopkins Homelike Environment Rating Scale. Correlates of quality of life are significant at the $p < .05$ level. age, gender, education, race, length of stay in assisted living, cost of assisted living, euphoria, sleep disturbance, and appetite and eating disorders were not significant.

[a]Hypothesis-driven facility variables were not significant.

Facility Variables as Moderators

Homelike environment and size were each individually entered into regression models with agitation or aggression, dysphoria or depression, apathy, and irritability to explore whether the relationships between neuropsychiatric symptoms and quality of life were moderated by facility factors. There were no significant effects for either of the potential moderators with the exception of a weak effect of size of facility on the relationship between agitation and quality of life. As agitation symptom severity increased, residents of larger facilities tended to have increasingly lower quality of life compared to those in smaller facilities (Figure 1). In a regression that included agitation, size, and the interaction variable (e.g., Size × Agitation symptom score), the amount of variance accounted for on quality of life increased from 19% to 20.3% (unstandardized $\beta = 14.42$, $p = .045$).

Discussion

The major aim of this study was to evaluate whether specific resident characteristics and environmental characteristics are associated with quality of life in residents of assisted living with dementia. The results demonstrate that agitation or aggression, depression, apathy, and irritability are significantly associated with

and cognitive function collectively accounted for 19.7% of the variance in quality-of-life scores. Agitation or aggression was again the strongest neuropsychiatric-symptom predictor, accounting for 15.7% of the variance. Dysphoria or depression was the second strongest predictor and accounted for 7.7% of the variance, followed by apathy and irritability (3.6% and 2.1% of the total variance of quality of life, respectively). The four neuropsychiatric symptoms collectively explained an additional 29.1% of the variance in quality of life.

Table 3. Multivariate Linear Regression Models with Significant Correlates of Quality of Life

Predictor Variable	β (SE)	P	Cumulative Adjusted R^2
Model 1[a]			
NPI-C (agitation or aggression)	−12.01 (2.88)	< .001	.212
NPI-G (apathy)	−8.90 (2.55)	.001	.124
PGDRS-P	−0.25 (0.12)	.036	.049
NPI-D (dysphoria or depression)	−9.47 (2.68)	.001	.051
Marital status	−6.00 (1.87)	.002	.037
NPI-I (irritability)	−6.56 (2.64)	.014	.016
MMSE	0.32 (0.13)	.015	.020
Model 2[b]			
Block I			
Age	−0.21 (0.14)	.124	.197
Gender	0.40 (2.24)	.865	
Marital status (dichotomous)	−6.40 (2.32)	.001	
Race (dichotomous)	−0.05 (2.25)	.981	
PGDRS	−0.26 (0.12)	.030	
MMSE	0.34 (0.14)	.013	
Block 2			
NPI-C (agitation or aggression)	−11.11 (3.04)	< .001	.157
NPI-D (dysphoria or depression)	−9.24 (2.81)	.001	.077
NPI-G (apathy)	−8.62 (2.78)	.002	.036
NPI-I (irritability)	−6.63 (2.75)	.017	.021

Notes: NPI-C, D, G, I = Neuropsychiatric Inventory; PGDRS = Psychogeriatric Dependency Rating Scale; MMSE = Mini-Mental State Exam. For Model 1, total adjusted R^2 = .509; for Model 2, total adjusted R^2 = .488.

[a]All significant variables were entered in stepwise regression.

[b]Demographics and covariates were entered in Block 1. Significant NPI symptom variables were entered stepwise into Block 2.

lower quality of life. These effects are significant even after controlling for other resident factors, such as demographics, functional impairment, medical health, and cognition. Agitation or aggression was the strongest predictor of quality of life, surpassing the influence of demographic covariates and other neuropsychiatric symptoms. Contrary to our hypotheses, environmental factors, specifically size and homelike setting, were not significant correlates of quality of life. Homelike environment and size also did not appear to moderate many of the affects of agitation, depression, apathy, or irritability on quality of life. Only a weak moderating effect of facility size on the relationship between agitation and quality of life was found. This may suggest that small facilities are better able to handle symptoms of agitation so that their negative effects on quality of life are mitigated in comparison to large facilities. Alternatively, this may be a spurious finding attributable to multiple comparisons.

The findings related to psychiatric symptoms are consistent with the results of Gonzalez-Salvador and colleagues (2000), who found that quality of life measured by the ADRQL was associated with depressive symptoms in long-term care residents with dementia. Sikorska

(1999) found that among assisted living residents with and without cognitive impairment, depressive mood was negatively associated with resident satisfaction.

Our results, however, were contrary to findings from two other studies. One, a study of nursing home and residential care residents with dementia in England that used the NPI to assess behavioral and psychological symptoms of dementia, did not find any significant associations with quality of life as measured by a direct observational technique (Ballard et al., 2001). We believe the discrepancy in results is best explained by the differences in the conceptualization and operationalization of quality of life between the two studies and possibly by differences in the sample composition. The above-mentioned study assessed quality of life using a direct observational technique while we employed a proxy-rated measure.

Secondly, the current study did not confirm the beneficial effects of the social environment, specifically levels of cohesion and conflict, reported by Cummings (2002). This difference could be explained by our use of an environmental measure (HHERS) that aimed to capture specific dimensions of the assisted living environment but that may not have been as sensitive to specific social aspects such as cohesion and conflict. Studies reporting the significant main effects of facility size on quality of life have been mixed (Kuhn et al., 2002; Sikorska, 1999). The lack of a relationship in the present study suggests that the relationship, if any, is subtle and complex. This issue bears further study.

The strengths of this study include the use of standardized assessments of diagnosis and the use of an expert consensus panel to make a final diagnosis. Another major strength is the use of a stratified random sample strategy to identify a representative sample of Maryland assisted living facilities.

This investigation has some limitations. First, the ADRQL is a proxy measure of quality of life. It is based on assumptions about the elements that make up quality of life and may not represent an individual's subjective experience. Secondly, since some of the elements of the ADRQL are behavioral, there may be a circular aspect to the predictive power of the NPI. To counteract this possibility, we conducted the same analyses after excluding the feelings and mood domain, the domain most heavily weighted with affective items. The finding that apathy and agitation or aggression still account for the majority of the variance suggests that these play an important role in nonmood domains of quality of life. Third, the ADRQL and NPI were both rated by the same caregiver; it is possible that a caregiver caring for a resident with severe neuropsychiatric symptoms may inadvertently rate the resident's quality of life lower. Fourth, the scale for homelike environment has not been used or tested in any other study and therefore has not demonstrated concurrent validity or test–retest reliability. We plan to further develop this measure in the longitudinal continuation of the Maryland Assisted Living Study. Lastly, the study sample included only assisted living facilities from the state of Maryland. Although it is difficult to know for certain, characteristics of people living in
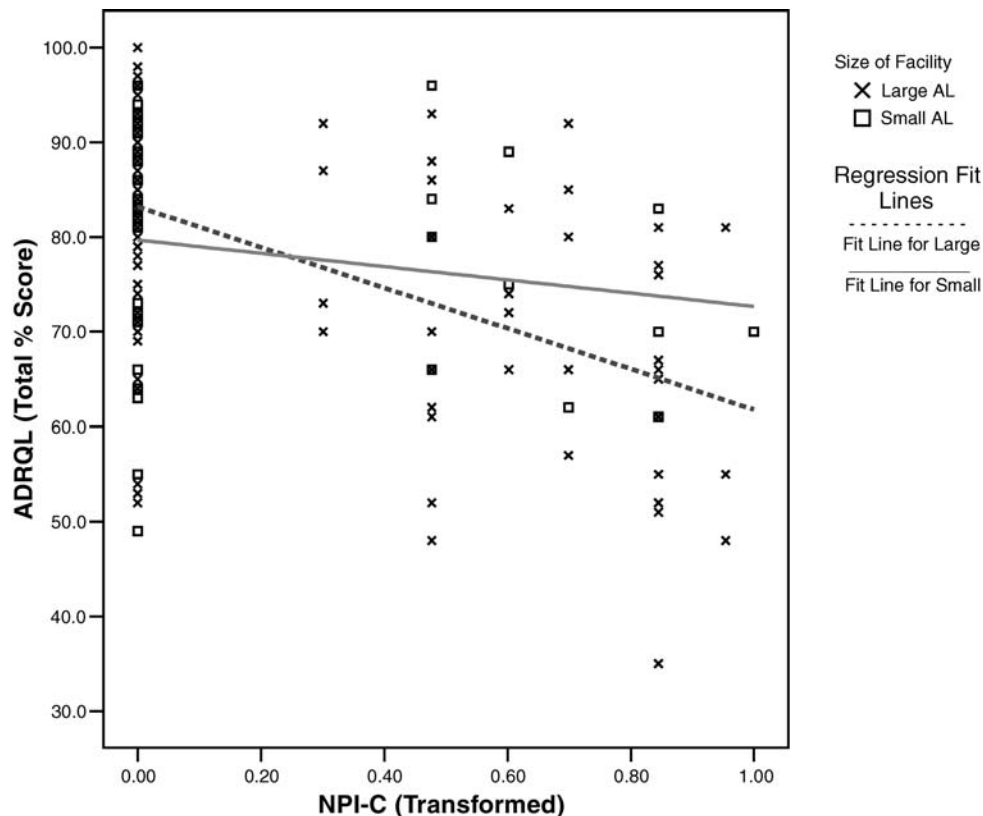
Figure 1. Interaction of agitation or aggression and size of facility on quality of life. ADRQL = Alzheimer's Disease-Related Quality of Life Scale; NPI-C = Neuropsychiatric Inventory (agitation or aggression).

assisted living may vary nationwide due to the lack of a uniform definition of assisted living.

In conclusion, neuropsychiatric symptoms, particularly symptoms of agitation and aggression, are independent correlates of quality of life in assisted living residents with dementia. While the care environment did not have a significant impact on quality of life in this study, further investigation in this area is needed. Future research should focus on the further identification of resident and environmental factors that influence quality of life in assisted living, the predictive power of these factors over time, and the effects of interventions targeting these factors.

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A Comparison of Three Methods of Measuring Dementia-Specific Quality of Life: Perspectives of Residents, Staff, and Observers

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Purpose: This exploratory study compared three methods of assessing dementia specific quality of life, corresponding to the perspectives of residents, staff members, and trained observers. **Design and Methods:** We collected data on 172 residents with dementia in four special care nursing facilities and three assisted living facilities. Analyses assessed the relationship of each quality-of-life method or perspective to the others and to resident characteristics such as cognitive and functional status. **Results:** The relationship of staff quality-of-life measures to resident characteristics varied by care setting while no significant relationships were found for resident quality-of-life measures. Staff and observational measures were moderately correlated in both settings. Moderate correlations of resident measures with staff and observational measures were found in the assisted living sample. **Implications:** Each perspective is relatively independent and somewhat unique. Measures that focus on specific aspects of quality of life may be more appropriate to use with assisted living residents than with residents of special care facilities.

Key Words: Dementia, Alzheimer's disease, Long-term care, Proxy questionnaires, Direct interviews, Observation

Whitehouse and Rabins (1992) argue that the quality of life of persons with dementia is ''not an isolated concept to be included as one of many measurements of the benefits of our care, but rather that it is the central goal of our professional activity'' (p. 136). Although good care may be a necessary condition for good quality of life, it is possible to provide good care without residents experiencing good quality of life. Thus, assessment of residents' quality of life should be a high priority in order to address unmet needs. In American nursing homes, information is routinely collected on quality-of-care indicators through the Minimum Data Set, but no data are collected related to quality of life. A major reason is the lack of knowledge about how to best measure the quality of life of persons with dementia, who constitute the majority of nursing home residents and a large and growing minority in assisted living facilities.

Assessment of dementia-specific quality of life in residential care facilities could have many benefits. The very act of inquiring about the quality of life of persons with dementia recognizes them as individuals rather than merely as care recipients. Staff also could use quality-of-life measures to identify the impact of interventions on residents. Relatives of individuals with dementia could better understand the status of their loved ones beyond the physical health indicators that are the basis of most care plans. Regulators could use quality-of-life measures to make their assessments more relevant in terms that make a difference in the lives of residents.

A number of dementia-specific measures have been developed over the past decade that attempt to assess

quality of life from three different perspectives. First, structured interviews have been developed that enable persons with mild to moderate dementia to self-report their quality of life (Brod, Stewart, Sands, & Walton, 1999; Kane et al., 2003; Logsdon, Gibbons, McCurry, & Teri, 2000, 2002). Second, questionnaires completed by family members and professionals have been developed to assess the quality of life of persons with dementia who are too impaired to communicate on their own behalf (Albert et al., 1996; Logsdon et al., 2000; 2002; Rabins, Kasper, Kleinman, Black, & Patrick, 1999). Third, measures of direct observation have been developed in which trained observers assess the quality of life of persons with dementia in congregate care settings (Bradford Dementia Group, 1997; Kitwood & Bredin, 1992; Lawton, Van Haitsma, & Klapper, 1996).

Despite progress in developing measures from these three perspectives, there has been little effort to simultaneously compare these perspectives and related measures. A quality-of-life study by Thorgrimsen and colleagues (2003) of 60 persons with dementia living in care facilities or attending day hospitals in the London area showed significant correlation between two self-report measures ($r = .69$, $p < .001$) and borderline correlation between a self-report measure and an observational measure ($r = .39$, $p = .051$). A study by Edelman, Fulton, and Kuhn (2004) of 54 individuals with dementia participating in adult day centers in the Chicago area found that the same two self-report measures used in the above study were significantly correlated ($r = .56$, $p < .0005$) but were not correlated with two staff proxy measures or an observational measure.

Given the absence of a "gold standard" for assessing quality of life among persons with dementia, a comparison of quality-of-life methods to one another can be informative. Patterns of differences and similarities in how methods "perform" can indicate the usefulness of various methods for different individuals in different care settings. This article reports findings of an exploratory study of three methods of measuring dementia-specific quality of life representing three different perspectives in two types of residential care settings. In order to identify appropriate revisions to the measures based on the study sample, we first analyzed the distribution and factor structure of the items and the psychometric properties of the measures. We then examined the relationship between dementia-specific quality-of-life measures and four measures of cognitive and functional impairment. Finally, we assessed the relationships among the quality-of-life measures.

Methods

Participants

We recruited a convenience sample of seven sites in a metropolitan area of the United States. Sites included four special care facilities that are dementia-specific nursing homes and three assisted living facilities with dementia-specific programs and staff trained in dementia care. We obtained informed consent from a key family member or legal representative of each study participant. Informed consent also was obtained directly from individuals with a Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975) score of 10 or greater. We obtained complete quality-of-life data from 172 people including 117 residents of special care facilities and 55 residents of assisted living facilities (91.5% of those for whom family member or legal representative consent was obtained).

Quality of Life Measures

We used three types of measures to assess dementia-specific quality of life: two direct interviews (with residents whose MMSE scores were 10 or higher), two questionnaires completed at each site by a staff person, and observations of residents by trained observers. Higher scores indicated a higher quality of life.

Direct interviews.—The Quality of Life–Alzheimer's Disease (Resident QOL-AD; Logsdon et al., 2000) is a 13-item structured interview to assess issues such as one's relationship with friends and family, physical condition, and mood. It was originally developed and tested for use among community-dwelling individuals with dementia and their primary family caregivers. Based on unpublished work by Edelman and Fulton, the QOL-AD was adapted for people in residential settings by dropping two items (money and marriage), and adding four items (people who work here, ability to take care of oneself, ability to live with others, and ability to make choices in one's life). The wording of three items was changed ("self as a whole" was changed to "self overall," "ability to do chores" was changed to "ability to keep busy," and "life as a whole" was changed to "life overall"). The adapted 15-item scale (used in the current study) was rated by residents using the original 4-point scale (poor, fair, good, excellent). We examined the internal consistency of the adapted scale ($\alpha = .92$). Scale scores were computed as the mean of nonmissing items. If more than 20% of the items of any case were missing, we excluded the case from the analyses.

The Dementia Quality of Life instrument (DQoL; Brod et al., 1999) is a 30-item interview consisting of five subscales. The internal consistency (range of $\alpha = .67$ to .89) and test–retest reliability (range of $r = .64$ to .90) of these subscales were reported. Items are rated on one of two 5-point scales (ranging from not at all to a lot, and never to very often). We excluded an optional single item that assesses overall dementia-specific quality of life from the analyses.

Scale scores were computed as the mean of nonmissing items. If more than 25% of the items of any case were missing, we excluded the case from the analyses.

Staff proxy reports.—The Staff QOL-AD (Logsdon et al., 2000) is the staff questionnaire version of the Resident QOL-AD interview. The internal consistency for the present study was .88. The Alzheimer's Disease-Related Quality of Life instrument (ADRQL; Rabins et al., 1999; Black, Rabins, & Kasper, 2000) is a 47–item measure consisting of five subscales (range of $\alpha = .77$ to .85). The dichotomous response option is agree/disagree. Scale scores were computed as the mean of nonmissing items. If more than 25% of the items of any case were missing, we excluded the case from the analyses.

Observation.—Dementia Care Mapping (DCM; Bradford Dementia Group, 1997) involves making detailed observations of up to eight persons at 5-minute intervals for up to 6 continuous hours in public areas only. DCM data collection ("mapping") involves recording a "behavior category code" (BCC), which defines the type of behavior or interaction that is being observed, and a well-being/ill-being (WIB) value, which indicates the level of well-being or ill-being observed (possible values = −5, −3, −1, +1, +3, +5). For each participant, we calculated the mean of all WIB values, which will hereafter be referred to as a "WIB score." Beavis, Simpson, and Graham (2002) reviewed the methodological literature related to dementia care mapping and concluded that DCM has good face validity and reliability, and based on other aspects of validity, DCM should be regarded as a moderately valid instrument. A full description of DCM appears in this issue (Brooker, 2005).

Independent variables.—We collected information related to age, gender, ethnicity, length of stay, dementia severity, function, depression, and comorbidity. The MMSE employs a 30-point scale to assess dementia severity. We used the 6-item Activities of Daily Living scale (ADL; Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963) to measure residents' functional impairment (e.g., toileting, bathing, dressing, etc). Scale scores, which we computed as a count of the total number of dependent ADLs, range from 0 to 6.

The Cornell Scale for Depression in Dementia (CSDD; Alexopoulos, Abrams, Young, & Shamoian, 1988) contains 19 items indicative of depressive symptoms ($\alpha = .86$). Possible responses on a 3-point scale were: 0 = absent, 1 = mild or intermittent, and 2 = severe or chronic. (The descriptor "chronic" was added for this study.) We computed the sum of all 19 items to determine prevalence of depression. Depression was operationalized as a score > 7 points, based on a cutoff score adopted by other researchers (Teresi, Lawton, Holmes, & Ory, 1997; Watson,

Garrett, Sloane, Gruber-Baldini, & Zimmerman, 2003). In addition, we computed the mean of the items for use as a covariate in the analyses.

We assessed comorbid medical conditions using the 11-item Cumulative Illness Rating Scale–Geriatrics (Miller et al., 1992). We assessed severity of comorbid conditions using a 5-point scale ranging from none to extremely severe. We computed the scale as the number of conditions rated with at least a mild degree of impairment.

Procedure

An experienced nurse at each site collected data on age, gender, race, length of stay, ADLs, depression, and comorbidity. Information was derived from medical charts, administrative records, clinical judgment, and personal knowledge about residents. Staff questionnaires were completed for all residents by a staff member at each site who was most familiar with residents. A research assistant assessed each resident's dementia severity using the MMSE and conducted interviews using both the QOL-AD and DQoL if the MMSE score was ≥ 10 ($n = 65$). Two highly trained and experienced mappers conducted observations of all residents using DCM. Interrater reliability for these mappers was examined (> 85% exact agreement for BCCs and WIB values). We observed each of the residents continuously on a weekday, typically between 9:00 a.m. and 3:00 p.m., for an average 6.1 hr or 73.3 5-min time frames. Per DCM scoring guidelines, we did not make observations when a resident was situated in a private area such as a bedroom or bathroom. Thus, the average number of usable observations per resident was 4.7 hr or 56.8 time frames.

Analyses

We examined demographic and other characteristics for the total sample and for the subsample of residents who provided direct interviews; differences between residents in special care facilities and assisted living facilities were analyzed. To explore the possibility that Resident and Staff QOL-AD subscales existed, or that existing subscales (DQoL subscales and ADRQL subscales) could be combined into general quality-of-life scales, we conducted exploratory factor analyses. Unless otherwise indicated, we extracted factors using maximum likelihood estimation and rotated using direct oblimin (an oblique rotation) with $\delta = 0$. We examined eigenvalues and scree plots to determine the number of factors to retain. For all analyses, factor loadings of 0.3 or higher were considered salient. We assessed the internal consistency of these scales by computing Cronbach's coefficient alpha and by examining inter-item and item-total correlations. To ensure adequate power, factor analyses and internal con-

Table 1. Resident Characteristics

Variable	Total Sample			MMSE = 10+		
	All Study Participants (N = 172)	SCF (N = 117)	ALF (N = 55)	All Study Participants (N = 65)	SCF (N = 38)	ALF (N = 27)
Age	85.8 (6.4)	86.0 (6.8)	85.3 (5.4)	85.6 (5.8)	85.3 (6.2)	86.1 (5.1)
Female (%)	83.7	85.5	80.0	81.5	86.8	74.1
White (%)	97.0	96.5	98.1	100	100	100
Length of stay (in days)	729.9 (581.1)	748.5 (593.3)	695.5 (561.7)	607.3 (543.4)	671.8 (618.9)	518.1 (412.5)
MMSE	9.0 (6.9)	7.9 (6.8)**	11.1 (6.8)**	15.6 (3.8)	15.1 (4.0)	16.5 (3.5)
Count of dependent ADLs	3.4 (2.2)	3.8 (2.2)**	2.5 (2.0)**	1.9 (1.9)	2.1 (2.2)	1.6 (1.3)
Depression	0.3 (0.3)	0.3 (0.2)	0.3 (0.4)	0.2 (0.3)	0.2 (0.2)	0.2 (0.3)
Prevalence	26.2%	21.4%	36.4%	18.5%	18.4%	18.5%
Count of mild to severe comorbidities	3.1 (1.7)	2.8 (1.5)*	3.6 (2.0)*	3.4 (1.9)	2.8 (1.5)**	4.3 (2.0)**

Notes: SCF = special care facilities; ALF = assisted living facilities; ADLs = activities of daily living; MMSE = Mini-Mental State Exam. For the table, data presented are M (SD) or % of total.

$*p < .05$; $**p < .01$.

sistency analyses were not conducted separately for residents in special care facilities and assisted living facilities.

To examine individual differences between the Resident and Staff QOL-AD, we computed difference scores by subtracting the Staff QOL-AD scale scores from the Resident QOL-AD scale scores and assessed the distribution of these difference scores by care setting. We computed Pearson correlation coefficients between the quality-of-life measures and MMSE, ADLs, depression, and comorbidities.

To examine differences among the more comprehensive quality-of-life scales (subscales that focused on specific components of quality of life were excluded), we conducted a repeated measures MANOVA with two factors: care setting (between subjects; special care and assisted living), and quality-of-life measure (within-subjects; four levels representing four measures). We conducted planned comparisons between the two resident measures and between the Staff QOL-AD and WIB scores. To determine differences between the Staff QOL-AD and WIB scores, we conducted a second multivariate repeated measures analysis of variance with the larger sample, not limited to residents who provided an interview.

To enable comparison and interpretation of findings using repeated measures multivariate analysis of variance, we recoded the scales into a common unit of measure. Because the Staff and Resident QOL-AD interviews share the same response options (1 to 4), the other scales were recoded into this response scale. The procedure used to recode scales changed the unit and origin of these scales and did not affect the distribution of the data or the relationships within the data (McCall, 2001). We also examined differences by care setting and used hierarchical multiple linear regression to determine the extent to which dementia-specific quality-of-life measures from each perspective could be predicted by measures from the other two perspectives.

Results

Resident Characteristics

As shown in Table 1, the sample consisted of 117 special care facility residents and 55 assisted living residents; data from 65 residents with MMSE scores of ≥ 10 were used for analysis of the two resident interviews. Residents were primarily female and Caucasian. The mean age was 85.8 years, and the average length of stay was about 2 years. Dementia severity, the number of dependent ADLs, depression severity, and the number of comorbidities are reported in Table 1. Special care residents were significantly more cognitively impaired, had more dependent ADLs, but had fewer comorbidities than assisted living residents.

Item Analysis

We found adequate use of the full range of potential responses, and response variability, as indicated by standard deviations, for the quality-of-life measures. The only exception was that some of the dichotomous items from the ADRQL had limited variability (up to 97.7% of the respondents chose one response option). Mean scores and standard deviations of the quality-of-life scales and subscales appear in Table 2.

Factor Analysis

DQoL.—The 29 items from the DQoL were factor analyzed. Because the rotated factors were

Table 2. Means and Standard Deviations of Original Scale Scores

Scale	Total Sample (N = 65)	SCF (N = 38)	ALF (N = 27)
Resident QOL-AD (range = 1–4)	3.1 (0.5) [1.3–4.0]	3.1 (0.5) [1.3–4.0]	3.1 (0.4) [1.8–4.0]
DQoL subscales (range = 1–5)			
Self esteem	3.7 (0.8) [1.3–4.8]	3.7 (0.7) [1.5–5.0]	3.8 (0.8) [1.3–5.0]
Positive affect	3.5 (0.7) [1.3–5.0]	3.5 (0.7) [1.3–5.0]	3.6 (0.7) [1.8–5.0]
Negative affect	2.1 (0.6) [1.0–3.7]	2.0 (0.6) [1.0–3.4]	2.3 (0.7) [1.1–3.7]
Feelings of belonging	3.4 (0.9) [1.3–5.0]	3.2 (0.9) [1.3–5.0]	3.6 (0.8) [1.3–5.0]
Sense of aesthetics	3.1 (0.9) [1.2–5.0]	3.0 (1.0) [1.2–5.0]	3.3 (0.8) [1.2–4.6]
	(N = 172)	(N = 117)	(N = 55)
Staff QOL-AD (range = 1–4)	2.4 (0.5) [1.3–3.7]	2.2 (0.4) [1.3–3.2]	2.9 (0.5) [1.5–3.7]
ADRQL subscales (range = 0–1)			
Social interaction	0.8 (0.2) [0–1.0]	0.8 (0.2) [0.3–1.0]	0.9 (0.2) [0–1.0]
Awareness of self	0.7 (0.2) [0.1–1.0]	0.6 (0.2) [0.1–1.0]	0.7 (0.2) [0.3–1.0]
Feelings and mood	0.9 (0.2) [0.3–1.0]	0.9 (0.1) [0.3–1.0]	0.9 (0.2) [0.3–1.0]
Enjoyment of activities	0.7 (0.3) [0–1.0]	0.7 (0.3) [0–1.0]	0.8 (0.2) [0–1.0]
Response to surroundings	0.8 (0.2) [0.3–1.0]	0.8 (0.2) [0.3–1.0]	0.8 (0.1) [0.3–1.0]
WIB	1.0 (0.8) [−2.4–2.8]	0.7 (0.8) [−2.4–2.3]	1.5 (0.4) [0.8–2.8]

Notes: SCF = special care facilities; ALF = assisted living facilities; QOL-AD = Quality of Life–Alzheimer's Disease; DQoL = Dementia Quality of Life; ADRQL = Alzheimer's Disease-Related Quality of Life; WIB = well- or ill-being. For the table, higher scores indicate better quality of life, except for negative affect for which a higher score indicates a higher level of negative affect. Data presented are M (SD); observed ranges are presented in brackets.

uncorrelated ($r = -.01$), we reanalyzed the items using an orthogonal rotation (varimax). The pattern of factor loadings clearly identified two factors: negative affect (comprising all 11 items from the Negative Affect scale) and general quality of life (comprising the remaining 18 items). These two factors accounted for 25.1% and 20.4% of the variance, respectively. Hereafter, these two factors will be referred to as Negative Affect and General DQoL.

Resident QOL-AD.—All 15 items from the Resident QOL-AD were factor analyzed. Two factors were identified and were significantly correlated ($r = .74$). The pattern of factor loadings in the structure matrix reflected this correlation; all items loaded on both factors. The factor loadings and factor correlations suggest that these two factors are indicative of a single factor, therefore all items were reanalyzed with a one-factor solution prespecified. Items loaded (range of loadings = .54 to .85) on this single factor and accounted for 51.8% of the variance.

Staff QOL-AD.—All 15 items from the Staff QOL-AD were factor analyzed. One factor was retained and accounted for 41.8% of the variance. Because four factors had initial eigenvalues greater than 1.0, we also explored the four-factor solution. The loadings revealed significant factorial complexity; 10 of the 15 items were loaded on three or four of the factors. Factor correlations ranged from $r = .01$ to .42. The factor loadings and correlations suggest that these factors are likely highlighting different dimensions of a single factor.

ADRQL.—All 47 items from the ADRQL were factor analyzed. Three factors were identified. The pattern of factor loadings indicated a fair degree of complexity; however, there were also some clear patterns. In addition to other items, all but two of the items from the Social Interaction subscale loaded on factor one; all but one of the items from the Awareness of Self subscale loaded on factor two. Items from multiple scales loaded on factor three. Factor one was significantly correlated with factors two ($r = -.31$) and three ($r = .24$), while factor two and three were not correlated ($r = .09$). These three factors accounted for 18.0%, 6.8%, and 4.0% of the variance, respectively.

Internal Consistency Reliability

An item was considered inconsistent and removed from the scale if it had negative interitem or item-total correlations, and/or the alpha would improve if removed. An alpha $\geq .70$ is considered adequate. Table 3 presents internal consistency statistics, including alpha and interitem and item-total correlations. For the Staff QOL-AD, we observed some negative correlations, indicating a need to revise this scale. Examination of these correlations indicated that one item (family) was not consistent with the remaining items. This item was removed and the alpha recomputed; item-total correlations improved.

The item-total correlations, interitem correlations and/or internal consistency alpha for the Social Inter-action, Awareness of Self, and Feelings and Mood subscale indicated a need to revise these scales. After

Table 3. Internal Consistency

Scale or Subscale	α	Correlation Ranges Interitem	Item Total
DQoL general scale and subscales			
General DQoL (N = 58)[a]	.90	−.09–.60	.37–.75
Self esteem (N = 58)	.70	.27–.46	.40–.52
Positive affect (N = 58)	.78	.17–.52	.44–.59
Negative affect (N = 58)	.95	.37–.80	.58–.84
Feelings of belonging (N = 58)	.61	.32–.38	.41–.45
Sense of aesthetics (N = 58)	.79	.27–.60	.47–.66
Resident QOL-AD (N = 65)	.94	.29–.74	.53–.82
Staff QOL-AD (N = 168)	.90	−.12–.80	−.05–.84
Revised (N = 170)[b]	.91	−.07–.79	.28–.85
ADRQL subscales			
Social interaction (N = 172)	.80	.01–.59	.11–.62
Revised (N = 172)[c]	.82	.07–.59	.34–.58
Awareness of self (N = 172)	.68	−.25–.60	−.24–.61
Revised (N = 172)[d]	.76	.14–.60	.30–.66
Feelings and mood (N = 172)	.71	−.10–.56	−.04–.56
Revised (N = 172)[e]	.74	.01–.56	.25–.59
Enjoyment of activities (N = 172)	.61	−.04–.42	.14–.55
Response to surroundings (N = 172)	.29	−.21–.45	−.01–.42

Notes: DQoL = Dementia Quality of Living; QOL-AD = Quality of Living–Alzheimer's Disease; ADRQL = Alzheimer's Disease-Related Quality of Life.

[a]This scale is comprised of all items from the from the following subscales: self-esteem, positive affect, feelings of belonging, and sense of aesthetics.

[b]The following item was removed: family.

[c]The following item was removed: He/She pushes, grabs, or hits people.

[d]The following item was removed: He/She becomes upset by personal limitations such as forgetting, losing things, or getting confused in familiar places.

[e]The following items were removed: He/She throws, hits, kicks, or bangs objects; He/She locks or barricades himself/herself in his/her room/house/apartment; He/She says he/she wants to die; He/She resists help in different ways such as with dressing, eating or bathing, or by refusing to move; and He/She clings to people or follows people around.

we removed inconsistent items, adequate scalar properties were achieved. The alphas of the Enjoyment of Activities and Response to Surroundings subscales were not adequate, and revisions did not substantially improve the alphas. Therefore, we did not include these subscales in the analyses. Because there is no generally accepted method of determining the internal consistency of WIB scores in DCM, we did not assess the internal consistency of these scores.

Correlations of QOL Measures With Dementia Severity, ADLs, Depression, and Comorbidities

The relationship of the quality-of-life measures to dementia severity, ADLs, depression, and comorbidities is shown in Table 4. In the special care subsample, the Staff QOL-AD and WIB scores were

Table 4. Correlations of Quality of Life Measures With Cognitive Severity, ADL Severity, Depression, and Comorbidities

Setting	N	MMSE	Count Of Dependent ADLs	Depression	Count of Mild to Severe Comorbidities
SCF					
Staff QOL-AD	117	.59*	−.58*	−.30*	.01
WIB		.42*	−.44*	−.24*	−.02
Social interaction		.38*	−.39*	−.15	−.14
Awareness of self		.62*	−.54*	.03	.03
Feelings and mood		.19	−.21*	−.30*	−.06
Resident QOL-AD	38	−.17	−.12	.08	.17
General DQoL		−.17	−.18	−.01	.19
Negative affect		−.28	.11	−.16	.19
ALF					
Staff QOL-AD	55	.22	−.21	−.68*	−.19
WIB		.30*	−.34*	−.24	.09
Social interaction		.37*	−.33*	−.76*	.18
Awareness of self		.45*	−.47*	−.11	−.01
Feelings and mood		.34*	−.29*	−.72*	.07
Resident QOL-AD	27	.01	−.07	.01	.08
General DQoL		.07	−.20	−.05	.06
Negative Affect		.08	−.06	.35	−.01

Notes: MMSE = Mini-Mental State Exam; ADLs = activities of daily living; SCF = special care facility; QOL-AD = Quality of Living–Alzheimer's Disease; WIB = well- or ill-being; DQoL = Dementia Quality of Life; ALF = assisted living facility.

*Significant at $p < .05$.

both significantly correlated with MMSE and count of dependent ADLs. However, in the assisted living subsample, WIB scores were significantly correlated with MMSE and count of dependent ADLs, while the Staff QOL-AD was not significantly correlated with either of these variables. Although the Social Interaction and Awareness of Self subscales demonstrated significant correlations with MMSE and ADLs in both subsamples, the Feelings and Mood subscale was significantly correlated with these variables in the assisted living subsample and was either not significantly correlated (MMSE) or not as strongly correlated in the special care subsample. Depression was significantly correlated with three of five staff/observer measures in both subsamples, but the correlations were considerably stronger in the assisted living sample. None of the quality-of-life measures were significantly correlated with the count of comorbidities. Also, none of the resident measures were significantly correlated with dementia severity, ADLs, depression, or comorbid conditions.

Table 5. Correlations Among Staff, Observer, and Resident QOL Measures

Setting	N	Staff QOL-AD	Social Interaction	Awareness of Self	Feelings and Mood	WIB
SCF						
Resident						
QOL-AD	38	.10	−.06	−.11	.25	−.00
General						
DQoL		.14	−.10	−.16	.08	−.03
Negative						
affect		−.30	−.11	−.04	−.25	.16
WIB	117	.40*	.28*	.32*	.29*	—
ALF						
Resident						
QOL-AD	27	.07	.26	.15	.09	.38*
General						
DQoL		.17	.20	.16	.18	.35
Negative						
affect		−.32	−.43*	−.12	−.41*	−.37
WIB	55	.31*	.22	.35*	.24	—

Notes: QOL = quality of life; QOL-AD = Quality of Life–Alzheimer's Disease; WIB = well- or ill-being; SCF = special care facilities; DQoL = Dementia Quality of Life; ALF = assisted living facilities.

*Significant at $p < .05$.

Comparison of Perspectives

Correlations among staff, observer, and resident quality-of-life measures.—Correlations among staff, observer, and resident quality-of-life measures are shown in Table 5. Because we focus on similarities and differences between perspectives in this article, correlations of measures from the same perspective are not reported. In the special care subsample, none of the resident measures are significantly correlated with any of the staff measures or WIB scores. In the assisted living subsample, however, the Resident QOL-AD is significantly correlated with the WIB; the Negative Affect subscale is significantly related to both the Social Interaction subscale and the Feelings and Mood subscale. In the special care subsample, the WIB is significantly correlated with the Staff QOL-AD, and three subscales—Social Interaction, Awareness of Self, and Feelings and Mood. In the assisted living subsample, the WIB is significantly correlated with the Staff QOL-AD and the Awareness of Self subscale. Because the special care subsample (*n* = 117) is much larger than the assisted living subsample (*n* = 55), differences between these settings in the significance of the correlations is, in part, determined by the difference in sample size.

Individual differences between Resident and Staff QOL-AD scores.—For this analysis, we retained the item in the Staff QOL-AD scale identified as inconsistent in the internal consistency reliability analyses to ensure that the Staff and Resident QOL-AD scales included equivalent items. Difference

Table 6. Means and Standard Deviations of Recoded Scale Scores

QOL Measure	Total Sample		Subsample With Resident Interviews	
	SCF (N = 117)	ALF (N = 55)	SCF (N = 38)	ALF (N = 27)
Staff QOL-AD	2.2 (0.4)	2.9 (0.5)	2.4 (0.4)	2.9 (0.4)
WIB	2.7 (0.2)	2.9 (0.1)	2.8 (0.1)	3.0 (0.1)
Resident QOL-AD	—	—	3.1 (0.5)	3.1 (0.4)
General DQoL	—	—	2.8 (0.5)	2.9 (0.5)

Notes: QOL = quality of life; SCF = special care facility; ALF = assisted living facility; QOL-AD = Quality of Living–Alzheimer's Disease; WIB = well- or ill-being; DQoL = Dementia Quality of Life.

scores, computed by subtracting the Staff QOL-AD from the Resident QOL-AD, ranged from −1.1 to 1.6 (*M* = 0.4, *SD* = 0.6). Most of the differences scores (69.2%) were positive, indicating the residents rated their own quality of life higher than staff rated them. To determine if these difference scores were related to dementia severity, we correlated difference scores with MMSE and found a significant correlation ($r = −.38$, $p = .002$).

For the special care and assisted living subsamples, difference scores ranged from −.9 to 1.6 (*M* = 0.6, *SD* = 0.6) and −1.1 to 1.4 (*M* = 0.2, *SD* = 0.6), respectively. These means were significantly different; $t(63) = 3.141$, $p = .003$, $d = 0.8$. Most difference scores (81.6% and 51.9%, respectively) were positive. Difference scores were significantly correlated with MMSE in the special care subsample ($r = −.53$, $p = .001$) but not in the assisted living subsample ($r = −.07$, $p = .738$).

Differences among the means of quality-of-life measures.—We conducted a repeated measures MANOVA to compare each of the two comprehensive resident measures with the Staff QOL-AD and WIB scores. We also examined differences by care setting (special care vs assisted living). The omnibus test indicated multivariate significance, $F(3, 61) = 17.829$, $p < .0005$; as well as a significant interaction, $F(3, 61) = 5.302$, $p = .003$. Planned comparisons indicated a significant interaction in which Staff QOL-AD scores were lower than General DQoL scores for residents of special care facilities but not for residents of assisted living facilities ($p = .013$, $\eta^2 = .095$). Similarly, Staff QOL-AD scores were lower than Resident QOL-AD scores for special care residents but not for residents of assisted living facilities ($p = .002$, $\eta^2 = .140$). There was also a significant difference between the Resident QOL-AD and WIB scores ($p = .002$, $\eta^2 = .144$) but no interaction with type-of-care setting. Examination of the means in Table 6 demonstrated that residents rated their quality of life higher than staff did in special care facilities but not assisted living facilities.

Due to the violation of certain assumptions of repeated measures MANOVA, we examined differences between the Staff QOL-AD and WIB scores using the nonparametric Wilcoxon Signed Ranks test. We conducted two tests, one for residents of assisted living facilities and one for residents of special care facilities. These tests indicated no significant differences in the assisted living sites ($p = .621$) but did indicate significant differences in the special care sites ($p < .0005$). Specifically, for 104 special care residents, the mean Staff QOL-AD score was less than the mean WIB score; for 13 residents the opposite was true. Means and standard deviations are reported in Table 6.

Predicting quality of life.—We used hierarchical multiple linear regression to examine the extent to which quality-of-life measures from each perspective could be predicted by measures from the other two perspectives. The three quality-of-life measures to be predicted include the Staff and Resident QOL-AD and WIB scores. We conducted three regressions. For these regressions, we dummy coded care setting, which was significantly associated with MMSE and ADLs (*t* tests, $p < .0005$), and tested on the first step, followed by the measures on the second step. We used forward entry in both steps.

Results of the first regression indicated no significant predictors of the Resident QOL-AD. In the second regression, after removing one outlying case ($n = 64$), care setting ($\beta = -.435, p = .001$) and the Awareness of Self subscale ($\beta = .247, p = .033$) were both significant predictors of WIB scores. Care setting (adjusted $r^2 = .15$) accounted for much more of the variance than the Awareness of Self subscale (adjusted $r^2 = .05$). However, a normal P-P plot indicated a potential problem with nonnormality in the distribution of WIB scores. Transformations of the data were unsuccessful in correcting this problem; thus, caution should be used when interpreting these results.

In the third regression, after removing one outlying case ($n = 64$) whose standardized residual was -3.5, care setting ($\beta = -.540, p < .0005$) and WIB scores ($\beta = .227, p = .033$) were both significant predictors of the Staff QOL-AD. However, care setting (adjusted $r^2 = .39$) accounted for much more of the variance than WIB scores (.04). We reran the second and third regression analyses with all independent variables tested on the first step; the results were the same as in the original analyses.

Discussion

This article compared and contrasted three methods of assessing dementia-specific quality of life corresponding to the perspectives of residents, staff, and observers. Our goal was to identify similarities and differences that would provide a better understanding of the extent to which each measure estimates quality of life.

We conducted psychometric analyses to identify the most appropriate scales to use in the sample. Factor analysis indicated that the DQoL resident interview (Brod et al., 1999) could be represented by two subscales: Negative Affect and General DQoL. We identified a single factor for the Resident and Staff QOL-AD scales; thus, they were used unaltered with the exception of dropping one item from the Staff QOL-AD. The internal consistency reliability of two of five of the original ADRQL subscales was unacceptable. Therefore, we included the following subscales and scores in the analyses: three ADRQL subscales (Social Interaction, Awareness of Self, and Feelings and Mood), Negative Affect, General DQoL, Resident QOL-AD, Staff QOL-AD, and WIB scores.

Correlations Among Quality-of-Life Measures and With Other Measures

Because there is no "gold standard" against which to compare the dementia-specific quality-of-life scales, we examined the relationships of each scale to other measures. Correlations of the scales to measures of dementia severity and ADL impairment provided insight into the meaning and potential uses of the quality-of-life scales. In special care facilities, Staff QOL-AD was more strongly correlated with MMSE and ADLs than were the staff subscales Social Interaction and Feelings and Mood. This finding may reflect the greater challenges faced by special care staff to engage more impaired residents and to notice variability in residents' emotions. By contrast, in assisted living facilities, higher correlations with MMSE and ADLs were found for Social Interaction and Feelings and Mood than with Staff QOL-AD. Assisted living residents, who are typically less impaired than special care residents, may have more opportunities for social engagement and communicating their feelings. Therefore, in contrast to special care facilities, it is likely that staff members of assisted living facilities will be more aware of residents engaging with others and take notice of their feelings and mood.

The staff measure Awareness of Self was most highly correlated with dementia severity and ADLs in both subsamples, suggesting that this scale is particularly sensitive to impairment level. Given the strong correlation between MMSE and ADLs ($r = .70; p < .0005$) and that the items comprising the Awareness of Self subscale reflect cognitive performance, it is likely that the relationship of Awareness of Self to impairment is driven by dementia severity.

Depression was more strongly correlated with staff measures in the assisted living subsample than in the special care subsample. Distinguishing between symptoms of depression and dementia may

have been a difficult task for staff in special care facilities whose residents demonstrated greater dementia severity. On the other hand, depression may have been more easily recognized in assisted living residents who were less impaired and had a better capacity to communicate.

None of the dementia-specific quality-of-life scales were significantly correlated with the count of comorbid conditions. Most of the comorbid conditions were mild in nature; thus, these conditions may have had little impact on residents' quality of life.

By contrast to the staff and observer measures, none of the resident scales were correlated with dementia severity, ADLs, depression, or comorbidities. A statistical explanation is not likely because we found the resident measures to have adequate distributional properties. As a result, limited variance in the measures is not an explanation for the low correlations. In this study, residents' self-perceived quality of life was unrelated to their cognitive and functional impairment. An explanation for residents' self-perceptions of quality of life remains to be determined.

Our finding that dementia severity and ADLs are correlated with staff and observer estimates of quality of life should not be interpreted to mean that moderately to severely impaired persons are limited to a poor quality of life. First, the limited amount of variance ($r^2 = .08$ to $.22$) accounted for by most of the significant correlations (16 of 23) suggests that much about residents' quality of life is not explained by dementia severity and ADLs. Secondly, a resident's perspective of one's own quality of life is not necessarily influenced by dementia severity and ADLs. Clearly, there is much to be learned about determinants of dementia-specific quality of life and how residents, staff, and observers gather and process information about quality of life.

Difference Between Resident and Staff/Observer Perspectives

Differential patterns of correlations among dementia-specific quality-of-life measures suggest that the perspectives of staff and observers were more closely aligned with each other than the perspective of residents in special care nursing facilities. For instance, we found moderate correlations between staff measures and WIB scores. In contrast, none of the correlations between resident measures and staff measures/WIB scores were significant (see Table 5). In that care setting, the perspective of residents was quite different than the perspectives of staff and observers.

Multivariate comparisons among all the quality-of-life measures revealed significantly lower scores on the Staff QOL-AD than on the General DQoL or the Resident QOL-AD, but only in the special care

subsample. WIB scores were significantly lower than Resident QOL-AD across both settings. Thus, the staff and the observer perspective indicated lower quality of life than did the residents' perspective, especially among the more cognitively impaired special care sample.

While it is tempting to assume that residents' with greater cognitive impairment were less able to make accurate judgments regarding their quality of life, it is also possible that staff were unable to make accurate estimates of residents' quality of life as they became less communicative due to dementia. Perhaps the criteria upon which staff made their quality-of-life judgments (e.g., engagement and positive affect) were not appropriate from the perspective of residents. For example, is the resident who is sitting quietly experiencing poor quality of life or is he or she simply meditating? Although this study cannot answer this question, a study that uses residents' physiological state as an outcome measure could be helpful.

Multiple regression findings indicated that type of care setting was a better predictor of WIB scores and Staff QOL-AD than other quality-of-life measures. This remained true when care setting was tested on the first step of the analysis followed by the quality-of-life measures or when all independent variables were tested together on the first step of the analysis. Strong associations of care setting with MMSE and ADLs (significant t tests, $p < .0005$), suggest that care setting may serve as a proxy for these variables. Resident QOL-AD was not predicted by any other variable. Thus, each of these three perspectives—resident, staff, and observer—remain fairly distinct with only a small proportion of the variance of staff or observer measures accounted for by the other quality-of-life measure.

Limitations

We should note several limitations of this study. The observed range of the WIB scores, the ADRQL subscale scores, the count of dependent ADLs, and the depression scores is somewhat limited; this may be limiting their correlations with other variables. The sample size was relatively small and confined to seven sites in a specific region of the United States and included a limited number of men and persons of color. These analyses need to be replicated with a larger, more representative sample. Another limitation is that the perspectives of those making quality-of-life judgments are confounded with the methods. Although the data-collection methods tested in this study represent the best means currently available, differences found could reasonably be attributed to either the method or the perspective. For instance, DCM uses trained observers to estimate quality of life in real time during a number of hours of observations, staff question-

naires provide judgments of quality of life based on staff members' overall estimate over a period of time, and residents' may respond in terms of their status at the moment they are interviewed.

Future Considerations

This study demonstrated the relative uniqueness of each perspective of quality of life. Different measures assessing the same perspective were not directly compared. Such a comparison could enable care providers to select the resident or staff measure that is most appropriate for regularly assessing quality of life. Ideally, a profile of quality-of-life scores across multiple perspectives could provide a complete picture of residents' quality of life, or an index could be developed which combines elements of multiple perspectives into a single score. To maximize the usefulness of quality-of-life measures in residential care settings, a national database of dementia-specific quality-of-life data should be developed that would refine measures in terms of psychometric properties, benchmark dementia care programs, and provide normative data. These data would not only be useful to service providers to better understand the impact of their programs but also would provide information for family members and potential residents to help them make informed choices regarding residential care options. To accomplish this goal, two parallel efforts should be undertaken. First, comparison studies, like the one presented in this article, need to be conducted with larger samples to further specify the properties of these measures and their relationship to each other and to quality of life. Second, service providers must be incentivized to collect quality-of-life data using one or more measures and contribute to a centralized data bank.

Maximizing the quality of life of persons with dementia should be a high priority for care providers. Utilization and further development of measures that account for multiple perspectives is critical to better understand how to best meet the needs of persons with dementia. Measuring quality of life enables care providers to focus on each person with dementia as a unique individual and provide the highest level of care in residential care settings.

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Evaluating the Quality of Life of Long-Term Care Residents With Dementia

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Purpose: This study's purpose was to better understand existing measures of quality of life in dementia residents of long-term care facilities. **Design and Methods:** We gathered data from 421 residents in 45 facilities. Analyses determined the psychometric properties of each measure, estimated the relationship between measures, and identified the extent to which resident characteristics predicted scores. **Results:** Most instruments had good to excellent dispersion and interrater reliability, and most scales had good to excellent internal consistency. Proxy measures tended to correlate best with each other, less well with observational measures, and least well with resident measures. Resident cognition and activities of daily living (ADLs) function were associated with most quality-of-life measures but predicted no more than a quarter of the observed variance in any measure. **Implications:** Various measures and sources of data provide different perspectives on quality of life. No "gold standard" exists; so a combination of methods and sources is likely to provide the most complete picture of quality of life.

Key Words: Quality of life, Long-term care, Dementia, Assisted living, Nursing homes

In recent decades, the focus of long-term care evaluation and research has gradually shifted from how care is delivered (process of care) to how care affects residents (outcomes of care). Accompanying this shift has been the recognition that the primary outcome of interest should not be quality of care provided by the facility but quality of life achieved by its residents. Defining and measuring quality of life has proved complex, however, especially when the concept is applied to individuals with Alzheimer's disease and related dementias.

Most definitions of quality of life are broad. The Institute of Medicine, for example, defined it as "subjective or objective judgment concerning all aspects of an individual's existence, including health, economic, political, cultural, environmental, aesthetic, and spiritual aspects" (Institute of Medicine, 2001). In a similar vein, M. Powell Lawton (1991) defined quality of life as "the multidimensional evaluation, by both intrapersonal and social-normative criteria, of the person–environment system of the individual" (p. 6). Some authors have tried to narrow the concept by considering only those aspects of quality of life that can be affected by health care interventions, using the term *health-related quality of life* to describe this construct (Noelker & Harel, 2001; Testa & Simonson, 1996). However, because long-term care facilities are therapeutic living environments in which the majority of resident activities involve and/or are structured by facility staff, health-related and overall quality of life may differ little in these settings. Another approach to narrowing the conceptualization of quality of life is to focus on a specific illness and the aspects of quality of life most affected by that illness, thereby creating a *disease-specific quality-of-life* measure.

A variety of theoretical models describe and organize the components of quality of life in ways

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that are relevant to the study of quality of life in long-term care settings. Bennett (1980) portrayed long-term care quality of life in terms of satisfaction of basic human needs: physiological, safety and security, social, self-esteem, and accomplishment. Lawton (1994) proposed four general sectors of quality of life: psychological well-being, behavioral competence, objective environment, and perceived quality of life. This and other writings by Lawton advanced the notion that quality of life has both an objective component (what the person experiences and does) and a subjective one (how the person feels about it) and concluded that quality of life would best be assessed from multiple perspectives. In contrast, Brod, Stewart, and Sands (2000) argued that the subjective element is the only "true" aspect of quality of life, and other aspects (e.g., environment, individual function, and behavior) are determinants of this subjective quality of life. Kane and colleagues (2003), building on the work of Lawton (1991), subscribed to the broader view and identified the following domains of long-term care quality of life: emotional health, physical health, functional status, comfort and security, social function, and self-worth or personal agency.

In addition to deciding what to assess, quality-of-life measurement in long-term care involves the issue of whose point of view to consider. Among the available options are resident report, staff report, family report, and direct observation. Deciding which point of view is most valid is particularly challenging in that quality-of-life assessments from different sources correlate poorly and exhibit systematic biases (Schnelle, 2003). Some have argued that the resident's subjective point of view should take precedence, and several instruments have been developed specifically for administration to persons with the disease (Brod et al., 2000; Logsdon, Gibbons, McCurry, & Teri, 2000). However, a significant proportion of persons with Alzheimer's disease—and the majority of long-term care residents with the disease—either cannot respond or provide responses of questionable validity due to lack of memory, inability to concentrate, lack of the capacity for introspection, unawareness of their impairments and disabilities, inadequate or absent language skills, thought disorders (e.g., psychosis), and/or acquiescent response bias (the tendency to be reluctant to complain; Kane et al., 2003; Lawton, 1994; Rabins, Kasper, Kleinman, Black, & Patrick, 2000; Schnelle). Because of these problems, many instruments to evaluate quality of life of individuals with Alzheimer's disease in long-term care use proxy respondents. Others have attempted to circumvent respondent bias by focusing on direct behavioral observation; but these, too, have limitations and inherent biases. Lawton (1997) elegantly argues that no "gold standard" measure of quality of life in dementia exists and that quality-of-life assessment should take into account both subjective and objective data from multiple sources. Thus, according to Lawton, understanding of quality of life "will be enhanced by looking for congruence and incongruence" between sources, and by attempting to explain observed differences in quality-of-life scores.

An additional area of controversy involves whether to report the components of quality of life separately or to combine them into a more global scale or index. According to Lawton (1997), reporting the components individually is more valid and clinically relevant than aggregating them into a composite score. This is because the components of quality of life are often considered to be independent of each other (Kane et al., 2003), and the relative value assigned to individual components varies markedly among the individuals whose quality of life is being assessed (Whitehouse & Rabins, 1992). For research and program-evaluation purposes, however, global measures are at times preferable, and researchers often attempt to combine multiple dimensions into a single scale.

The past decade has seen elaboration of a variety of instruments that were designed to measure quality of life for persons with Alzheimer's disease. They range from single-component measures to those that evaluate multiple domains. They include instruments that involve resident report, staff report, and direct observation. To date, with the exception of one other report in this issue (Edelman, Fulton, Kuhn, & Chang, 2005), no efforts have comprehensively evaluated these new measures against one another to identify if one is optimal for evaluating quality of life among persons with Alzheimer's disease who reside in long-term care.

This article reports the results of a comparative study of many of the existing disease-specific quality-of-life measures for Alzheimer's disease. The study was undertaken to better understand the contributions of existing measures to the description and evaluation of quality of life among persons with Alzheimer's disease who reside in long-term care facilities. The measures we studied include those administered directly to residents, those that question staff proxies, and those that involve direct observation. The study was designed to address the following questions: What are the completion rates and psychometric properties of different measures in long-term care settings? To what extent are scores on the various instruments correlated? How do responses from different sources compare? And, finally, given the effort involved in collecting quality-of-life data, to what extent do these instruments provide information beyond what can be predicted using easily obtained information on resident health status?

Design and Methods

As part of a study of dementia care in residential-care and assisted-living facilities and nursing homes,

Table 1. Measures Studied and Domains of Quality of Life Addressed by Each Measure

Instrument	Data Source	Domains of Quality of Life
Quality of Life in Dementia (QOL-D; Albert)	Care provider and/or resident (two versions)	Activity participation (both versions) Positive and negative affect (care-provider version only)
Quality of Life in Alzheimer's Disease (QOL-AD; Logsdon)	Care provider and/or resident (two versions)	Relationships with family and friends, concerns about finances, physical condition, mood
Alzheimer's Disease Related Quality of Life (ADRQL; Rabins)	Care provider	Social interaction, awareness of self, feelings or mood, enjoyment of activities, response to surroundings
Dementia Quality of Life (DQoL; Brod)	Resident	Self-esteem, positive affect or humor, negative affect, feelings of belonging, sense of aesthetics (enjoyment from five senses)
Dementia Care Mapping (DCM)	Observation	Activity, well- and-ill-being
Resident and Staff Observation Checklist (RSOC-QOL)	Observation	Agitation, physical contact, and engagement
Philadelphia Geriatric Center Affect Rating Scale (PGC-ARS)	Observation	Positive and negative affect

Notes: Because the names and acronyms of the QOL-D, QOL-AD, ADRQL, and DQoL are so similar, for clarification they are referred to in this and subsequent tables by the name of their primary author as well as their name.

we gathered data from 421 residents in 45 facilities in four states.

Facility Sample and Study Participants

Study participants were enrolled from a purposive sample of 45 facilities in four states: Florida, Maryland, New Jersey, and North Carolina. We selected facilities from an existing cohort of 233 facilities, with additional facilities recruited at the recommendation of an advisory committee from the Alzheimer's Association, toward the overall goal of including a wide range of facilities in terms of licensure, structure, and process of care. Of the facilities enrolled, 35 were licensed as residential-care and assisted-living facilities, defined as any facility licensed by the state at a nonnursing home level of care that provided room and board, assistance with activities of daily living (ADLs), and 24-hr supervision or oversight. Of these residential-care and assisted-living facilities, 14 were "small" ($<$ 16 bed) homes, 10 were new-model facilities ($\geq$ 16 beds, built after 1987, and exhibiting one or more characteristics associated with the care of higher-acuity residents), and 11 were traditional facilities ($\geq$ 16 beds, not meeting the new-model criteria). The remaining 10 study facilities were nursing homes. Descriptions of the typology are available elsewhere (Zimmerman et al., 2001).

Within our 45 study facilities, all residents who were aged 65 years or older and had a diagnosis of dementia were identified. To limit the sample to the common forms of age-related dementia, residents were excluded if they had a primary diagnosis of Huntington's disease, alcohol-related dementia, schizophrenia, manic-depressive disorder, or mental retardation. To maintain representation across

facility types, we targeted a maximum of 4 residents per smaller facility and 19 residents per larger facility for enrollment; we approached eligible residents in each facility in random order until the maximum was reached. We obtained consent directly from residents who were judged by facility staff to have the capacity to consent; for those too cognitively impaired to provide their own consent, we approached a guardian or responsible party for consent. Of 575 eligible residents approached for consent, 421 (73%) agreed to participate, 66 (11%) refused, and 88 (15%) were unable to provide consent and had responsible parties who were unreachable. Participant enrollment and consent followed guidelines approved by the Institutional Review Boards of the School of Medicine of the University of North Carolina at Chapel Hill and the School of Medicine of the University of Maryland–Baltimore.

Measures

Table 1 displays the quality-of-life measures studied and data sources and provides an overview of the domains of quality of life addressed by each. The instruments are described below.

Quality of Life in Dementia (QOL-D; Albert et al., 1996).—This instrument was developed based on the assumption that the experience of living was the key component of quality of life and that readily observable behaviors would offer insight into the experiential world of persons with dementia. It measures two dimensions: activity and affect. The activity component was derived from Teri and Logsdon's Pleasant Events Schedule-AD (Logsdon

& Teri, 1997; Teri & Logsdon, 1991). It contains 15 items, 5 of which involve travel outside. Each item is rated over a one-week timeframe for opportunity and engagement in the activity. Response categories are frequently ($\geq$ 3 times per week), occasionally ($\leq$ 3 time per week), or never. The activity variables can be combined into a summary activity measure, which ranges from 0 to 30, with higher scores indicating more activity.

The affect component of the QOL-D was derived from Lawton's Affect Rating Scale (Lawton, Van Haitsma, & Klapper, 1996); it contains 6 items, 3 of which measure positive affect and 3 of which measure negative affect. Each item is coded for its average frequency during the previous 2 weeks. Frequency is coded on a 5-point format, ranging from never (coded as 1) to 3 or more times a day (coded as 5). Summary positive and negative scores (each ranging from 3 to 15) are calculated.

Two versions of the instrument exist: a care provider version, which is completed by a proxy and rates both activity and affect; and a resident version, which is completed by the person with dementia and rates only activity. Both versions were independently administered and evaluated in this study. For the caregiver version of the affect items, test–retest reliability was reported to be between 0.53 and 0.92; for 12 of the 15 activity items, Kappas were above 0.60 (Albert et al., 1996).

Quality of Life in Alzheimer's Disease (QOL-AD; Logsdon et al., 2000).

—This instrument evaluates one's physical condition, mood, interpersonal relationships, ability to participate in meaningful activities, and financial situation. The original measure had 13 items; however, the measure evaluated in this study was a 15-item modification for use in long-term care, in which "relationships with people who work here" was substituted for "marriage relationship," "ability to keep busy" was substituted for "ability to do chores," and "ability to take care of self" was substituted for "ability to handle money;" "ability to make choices in (one's) life" and "ability to live with others" were added as new items (Edelman et al., 2005). Each item is rated on a 4-point scale (1 = poor and 4 = excellent), yielding a summative score ranging from 15 to 60.

The QOL-AD has two versions; one is designed to be administered to a care provider, the other directly to the person with Alzheimer's disease. The reported coefficient alpha for the patient version is 0.88 and for the caregiver version is 0.87 (Logsdon et al., 2000). In this study, both versions were independently administered and evaluated.

Alzheimer Disease Related Quality of Life (ADRQL; Rabins et al., 2000).

—This instrument consists of 47 items, completed by a care provider, that describe behaviors that were judged by focus groups of family caregivers and professionals to be of importance to health-related quality of life in Alzheimer's disease. The items address the following 5 domains: social interaction, awareness of self, feelings and mood, enjoyment of activities, and response to surroundings. The various domains contain from 5 to 15 items, each of which is rated and scored as either agree or disagree. Items are assigned weights, ranging from 9.15 to 13.51, which were designed to reflect the extent to which the item influences quality of life. Summary scores are generated for each domain and for global quality of life; each is computed so as to range from 0 (lowest quality) to 100 (highest quality). The internal consistency reliability of the ADRQL domains has been reported to range between 0.77 and 0.91 (Lyketsos et al., 2003).

Dementia Quality of Life (DQoL; Brod, Stewart, Sands, & Walton, 1999).

—This instrument was designed for direct administration to individuals with dementia to evaluate feeling states that comprise "the subjective experience of dementia." Its 29 questions address five domains: self esteem, positive affect and humor, negative affect, feelings of belonging, and sense of aesthetics. Items ask how often the respondent has experienced the feeling; responses are on a 1-point scale, ranging from 1 = never to 5 = very often. Each domain generates a scale, consisting of the mean of component items. Reported test–retest reliability for the 5 scales ranges from 0.64 to 0.90; internal consistency reliability for the scales ranges from 0.67 to 0.89 (Brod et al.). The DQoL was field tested in persons with mild and moderate, but not severe, dementia. The authors suggest that the instrument be supplemented by proxy assessment of more objective quality-of-life components, such as physical function, activity, and social interaction.

Dementia Care Mapping (DCM; Bradford Dementia Group, 1997; Fossey, Lee & Ballard, 2002; Kitwood, 1997).

—Based on theory articulated by Kitwood, DCM records observations every 5 minutes on activities (assigning a behavior category code [BCC]) and perceived quality of life (assigning a well- and-ill-being [WIB] score). To assign a BCC, the observer selects from a list of 24 codes the one that best describes the resident's behavior during the 5-minute observation period. Most BCCs fall into two categories: Type I codes (for good behaviors, such as conversation or creative expression) and Type II codes (for bad behaviors, such as being socially withdrawn or engaging in repetitive self-stimulation). There are three additional codes that are neither Type I nor Type II because their relation to well- or ill-being depends on context: sleeping, speaking, and locomotion. To assign a WIB score, the observer follows a complex set of rules, which

are specific for each BCC. Possible WIB scores are +5, +3, +1, −1, −3, and −5, with +5 representing the highest state of well-being, −5 representing the worst state of ill-being, and +1 as a neutral score. Interrater reliability on DCM items has been calculated using the concordance coefficient, and reported concordances have ranged between 0.70 and 0.95 (Beavis, Simpson, & Graham, 2002). Test–retest reliability was estimated using the correlation of item proportions; reported values are 0.55 for the considerable (+3/+5) well-being score and 0.40 for activities (Fossey et al.). DCM was developed as a quality-improvement tool; however, interest has recently grown on its possible use as a quality-of-life measure.

The standard DCM observational protocol for quality-improvement purposes calls for 6 hr of observation during the day, without specification of the time of day, and for observations to be made only in public areas. In this study, research observations were conducted over three specified one-hr intervals and did not exclude observation in resident rooms. The following DCM-based indicators of quality of life were evaluated: mean WIB score, percent of WIB values that were +3 or +5, and the percent of BCC observations that were in Type I categories.

Resident and Staff Observation Checklist—Quality of Life Measure (RSOC-QoL; Sloane et al., 1991; Sloane et al., 1998; Zimmerman, et al., 2001).—The RSOC-QoL was developed over 15 years of long-term care work by the study team. The instrument uses systematic nonparticipant observation to gather and record data on the appearance, location, activity, behavior, affect, restraint use, and interactions of residents in long-term care settings. For this study, observations were made every 5 min on study participants during 3 one-hr observation periods. Three measures of resident QOL are reported here: agitation, physical contact, and engagement. Agitation was coded as present if any one of nine behaviors (e.g., pacing or repetitive mannerisms) was observed; a summary score consisted of the percent of observations during which agitation was observed. Physical contact with other residents, staff, or visitors was coded as 0 = no contact, 1 = nonintimate touch (e.g., physical assistance), or 2 = intimate touch (e.g., hand holding). Engagement was coded as 0 = idle, 1 = watching, passive, or listening (alert and observing surroundings), or 2 = active (directly participating and/or interacting with environment). Quality-of-life summary indicators for physical contact and engagement were created by summing the scores over all observation periods for which data were available and then expressing the result on a scale from 0 to 100, such that 0 = a mean score of 0 for all observations and 100 = a mean score of 2 for all observations.

Reported interrater agreement of RSOC items ranged from 0.95 to 1.00 (Sloane et al., 1998).

Philadelphia Geriatric Center Affect Rating Scale (PGC-ARS; Lawton, 1994; Lawton et al., 1996).—This observational instrument was developed to assess quality of life by observing and noting the facial expression, body movement, and other cues by which persons with dementia communicate their minute-to-minute feeling states. The original instrument used multiple 10-min observation periods, during which research assistants recorded the prevalence of six affect states; these were then aggregated into two scales, positive affect and negative affect. Interrater reliability, using the Kappa statistic, was reported to range from 0.76 to 0.89 (Lawton et al.).

The measure used in this study was a modification based on reliability studies and experience with videotaped ratings of persons with dementia by the project team. Its seven states are mild pleasure, high pleasure, anger, anxiety or fear, sadness, general alertness, and sleeping or dozing. Data were recorded every 5 min during 3 one-hr observation periods; only one affect (the predominant state) was recorded per observation period. For the analyses reported herein, the affect states were coded as follows: 0 for anger, anxiety or fear, or sadness; +1 for general alertness or sleeping or dozing; +2 for mild pleasure; and +3 for high pleasure. These were summed during the observation periods and expressed on a scale from 0 to 100, such that 0 = a mean score of 0 for all observations and 100 = a mean score of +3 (maximum positive affect) for all observations.

Other measures.—A variety of measures were administered to gather data on the study participants and the facilities in which they resided. For these analyses, the following measures of resident function were used: the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975), the Minimum Data Set Cognition Scale (MDS-COGS; Hartmaier, Sloane, Guess, & Koch, 1994), the MDS scale of activities of daily living (MDS-ADL; Morris, Fries, & Morris, 1999), the Cornell Scale for Depression in Dementia (CSDD; Alexopoulos, Abrams, Young & Shamoian, 1988), the Cohen-Mansfield Agitation Inventory (CMAI; Cohen-Mansfield, 1986), and the Philadelphia Geriatric Center Pain Intensity Scale (PGC-PIS; Parmelee, Katz, & Lawton, 1991).

Data Collection

Data were collected on-site between September 2001 and February 2003 by teams of two or three trained study research assistants, which spent between 2 and 6 days in each facility, depending

on facility size. For each resident, interviews were conducted with the resident, the direct care provider who knew him or her best (i.e., the staff member who provided the most hands-on care, usually a nursing assistant), and the care supervisor who knew him or her best (i.e., the staff member directly above the direct care provider, usually a licensed nurse). In addition, observations were conducted on study participants by trained research assistants for one day. Finally, the administrator of each facility was interviewed to obtain facility-level data.

Data on the QOL-D (Albert et al., 1996), QOL-AD (Logsdon et al., 2000), and ADRQL (Rabins et al., 2000) staff measures were gathered from the direct care provider who knew the resident best. Data on the QOL-D, QOL-AD, and DQoL (Brod et al., 1999) resident measures were gathered directly from the resident. Participants with MMSE scores less than 10 were not administered the resident version of the QOL-D or QOL-AD, and residents who failed the DQoL cognitive screen were not administered the DQoL. Data on the observational measures were collected on up to 12 study participants in each facility; in sites with more than 12 participants, observation residents were randomly selected. A data collector observed up to three residents simultaneously using a nonparticipant method that recorded observations every 5 min for 3 hr (10–11 a.m., 1–2 p.m., and 4–5 p.m.); closed doors to resident rooms were opened during data collection (once per hour), after knocking, and observations were not made on residents who were behind bathroom doors or were off the unit.

Interrater reliability data on the study measures were collected during data-collection site visits. For the care-provider-reported measures, an interrater reliability study was conducted using a convenience sample of 23 staff care providers in five facilities by having one data collector conduct the interview while another data collector observed. The responses were independently recorded and scored, and an intraclass correlation coefficient was computed for each summary quality-of-life measure. For the measures based on direct observation, two data collectors simultaneously but independently observed up to three residents at a time, recording observations every 5 min for one hr (not during mealtimes). A total of 59 pairs of one-hr observations were recorded and scored on a convenience sample of 38 residents in seven facilities, using four data collectors. Intraclass correlation coefficients were computed for each observed quality-of-life measure.

Data Analysis

Descriptive statistics, including means, standard deviations, range, and medians were computed for all quality-of-life measures. MMSE scores were used to estimate the degree of cognitive impairment among participants (≥ 17 = mild impairment, 10–16 = moderate impairment, 3–9 = severe impairment, and ≤ 2 = very severe impairment); when an MMSE was not available (51 residents), corresponding ranges of the MDS-COGS were used. In order to determine whether the measures might be limited by ceiling or floor effects, the proportions of the sample scoring the minimum and maximum possible values for each measure also were calculated. For all multi-item measures, consistency reliability was estimated using Cronbach's alpha. To facilitate comparison across respondent type, for measures collected from both resident and care provider report (Albert's Patient Activities Score and Logsdon's QOL-AD), descriptive statistics were computed separately for both the full care-provider sample and the subset for which both care provider and resident data were available. To estimate the association between subscale scores and between different quality-of-life measures, Pearson correlation coefficients were computed between all measures.

To estimate the extent to which each quality-of-life measure was "explained" by commonly assessed measures of resident status, a series of seven hierarchical linear models was computed for each quality-of-life outcome measure. The first model contained no fixed effects and was used to derive an estimate of the total variance in each quality-of-life measure. Five additional models each adjusted for a single resident factor as follows: cognitive function (measured by the MMSE), disability in ADLs (number of dependencies among seven MDS-ADL items), depressive symptoms (CSDD), agitated behavior (CMAI), and pain (PGC-PIS). The final model included all five of these factors. For each model, variance reduction was computed as the percent decrease in the total variance for the model of interest from the total variance from the model without fixed effects; total variance is defined as the sum of resident, care-provider (or observer), and facility-level variances from the hierarchical linear model. For care-provider-reported quality-of-life measures, models included random effects for facility and care provider (nested within facility). For the resident-reported measures, models included a random effect for facility. For the directly observed measures, models included random effects for facility and observer.

Results

Characteristics of Study Facilities and Participants

The 35 residential care/assisted living (RC/AL) facilities in the study sample had a mean of 49 beds (range: 6–64) and a mean age of 13 years (range: 1–50), the majority (75%) were for-profit facilities, and half had a dementia special care unit. The 10 nursing homes in the sample had a mean of 114 beds (range: 50–180) and a mean age of 40 years (range: 12–105),

40% were for-profit facilities, and 80% had a dementia special care unit.

A total of 414 facility residents were included in these analyses. Residents who served as study participants had an average age of 85 years old (range: 65–101). The majority were female (79%) and White (91%). The degree of cognitive impairment among study participants was as follows: 12% were mildly impaired, 25% were moderately impaired, 27% were severely impaired, and 37% were very severely impaired. Supervisor interviews included diagnostic information on 326 participants (the remainder were either not completed or partially completed); of these, 54% had Alzheimer's disease, 4% had vascular dementia, 5% had both Alzheimer's disease and vascular dementia, and 37% had a nonspecific dementia diagnosis.

Psychometric Properties of the Quality-of-Life Measures Studied

Psychometric properties of the dementia quality-of-life measures studied are presented in Table 2. For the reported measures, the completion rate for the resident-completed instruments was 25–30%, whereas close to 100% of participants had care-provider versions completed. All of the reported measure scales and subscales demonstrated broad ranges and distributions that were approximately normal, with means and medians that were relatively similar (i.e., not markedly skewed). The three exceptions were the QOL-AD positive affect scale and two of the ADRQL subscales. Internal consistency was as follows: the QOL-D scales were largely in the good range (.57–.79); the QOL-AD was in the excellent range (.88–.92); the ADRQL overall scale was excellent (.85), but subscales ranged from fair to good (.46–.72); and the DQoL scale and subscales ranged from good to excellent (.59–.91). Interrater reliability of all reported measures was excellent.

For the observed measures (Table 2), nearly all participants (97%) selected for sampling had observations completed. Interrater reliability of the observed measures ranged from .28 (for the percentage of WIB scores in the +3 to +5 range) to .90 (for observed agitated behaviors); most were in the good to excellent range. Among the DCM measures, the mean WIB scores tended to cluster around 1 ($M = 0.74$, $SD = 0.55$). The percent of WIB scores of +3 or +5 demonstrated floor effects, with 68% of participants scoring 0%. In contrast, the percent of BCC Type I observations demonstrated good dispersion. Among the RSOC-QOL variables, both the agitated behaviors and physical contact demonstrated floor effects, whereas activity level or engagement and emotion or affect demonstrated more normal distribution properties.

Correlations Between the Quality-of-Life Measures Studied

Tables 3–8 display correlation matrices comparing the various quality-of-life measures with each other, by data source. In general, measures generated by care-provider report demonstrated moderate correlations with each other (Table 3), as did measures generated by resident report (Table 4). Correlations were lower, however, when care-provider reports were compared with those generated by residents themselves (Table 5). Of particular note are the low correlations observed when residents and care providers were administered the same instrument (0.24 for the QOL-D activities scale and 0.02 for the QOL-AD).

Correlations between the observational measures were in the low to moderate range (Table 6). In general, the observational items tended to correlate more strongly with care-provider reports (Table 7) than with resident reports (Table 8).

Extent to Which Resident Factors Explain Variation in Quality-of-Life Scores

Table 9 displays the proportion of variation in the results of each measure explained by five resident factors: cognitive function, physical function (ADLs), depressive symptoms, agitated behavior, and pain. Results are displayed as the percent of variance in each measure explained by each of these resident factors and by the combination of resident factors; they were generated by a series of hierarchical linear models in which the quality-of-life outcome was the dependent variable and the resident characteristics were the independent variable(s). For these analyses, the sample size was reduced so as to only include participants for whom data were available for all variables in the model. As a result, the total sample size is 246 for the care-provider-reported measures, 222 for the observed measures, and 78 for the resident-reported measures.

Of the five resident factors studied, cognition and ADL function were the strongest predictors of quality-of-life scores (Table 9). Nearly all care-provider-reported and observed measures tended to decline as cognitive function declined or ADL dependency rose. Depressive symptoms and agitation also were associated with many of the reported and observed measures, although the percent of variation explained was less. Pain, however, showed little association with any measure of quality of life. When all five measures of resident status were entered into predictive models, they were found to be associated with virtually all care-provider-reported and observed measures, with the proportion of variance explained being in the small to moderate range (0–27%). In contrast, little or no association was detected between any of the resident-reported measures and resident factors. Due to the small

Table 2. Psychometric Properties of Dementia Quality-of-Life Measures Studied

Measure	No. of Participants	Completion Rate (%)[a]	No. of Items	Theoretical Range	Observed Range	M (SD)	Median	Maximum (%); Minimum (%)[b]	Internal Consistency[c]	Interrater Reliability[d]
Reported measure										
QOL-D (Albert)										
Care provider (CP) report										
Activities	400	96.6	15	0–30	0–28	9.3 (5.0)	9	0; < 1	.78	0.95 (n = 18)
Positive affect	403	97.3	3	3–15	3–15	11.9 (2.9)	13	26; < 1	.66	0.99 (n = 23)
Negative affect	383	92.5	3	3–15	3–15	6.7 (3.1)	6	2; 16	.66	0.96 (n = 21)
Resident report										
Activities	110	82.1[e]	15	0–30	0–25	9.5 (5.1)	9	0; < 1	.78	0.99 (n = 5)
CP–resident subset[f]										
Activities	107	NA	15	0–30	0–26	10.1 (5.0)	9	0; < 1	.79	—
Positive affect	107	NA	3	3–15	5–15	11.9 (2.8)	12	25; 0	.57	—
Negative affect	103	NA	3	3–15	3–15	7.2 (3.1)	7	2; 12	.65	—
QOL-AD (Logsdon)										
Care provider report	410	99.0	15	15–60	19–59	36.9 (7.9)	37	0; 0	.88	0.99 (n = 20)
Resident report	121	90.3[e]	15	15–60	18–60	42.8 (8.2)	44	< 1; 0	.92	1.0 (n = 5)
CP–resident subset[f]	116	NA	15	15–60	24–59	41.1 (7.9)	41	0; 0	.89	—
ADRQL (Rabins)										
Social interaction	413	99.8	12	0–100	0–100	78.4 (18.5)	84	16; < 1	.69	1.00 (n = 23)
Awareness of self	410	99.0	8	0–100	9.3–100	66.7 (23.4)	73	9; 0	.62	0.90 (n = 20)
Feelings and mood	412	99.5	15	0–100	14.4–100	76.8 (18.0)	81	11; 0	.72	0.98 (n = 23)
Enjoyment of activities	411	99.3	5	0–100	0–100	68.1 (26.2)	78	24; 2	.50	0.97 (n = 22)
Response to surroundings	410	99.0	7	0–100	0–100	81.4 (18.6)	84	33; < 1	.46	1.00 (n = 22)
Total	410	99.0	47	0–100	21.0–100	75.2 (14.8)	78	1; 0	.85	0.99 (n = 22)
DQoL (Brod)										
Self-esteem	100	74.6[e]	4	1–5	1–5	3.5 (0.9)	4	8; 2	.73	1.0 (n = 5)
Positive affect or humor	97	72.4[e]	6	1–5	1–5	3.5 (0.9)	4	4; 2	.84	1.0 (n = 5)
Negative affect	97	72.4[e]	11	1–5	1–5	3.6 (0.8)	4	2; 1	.88	1.0 (n = 5)
Feeling of belonging	100	74.6[e]	3	1–5	1–5	3.3 (0.9)	3	4; 1	.59	1.0 (n = 5)
Aesthetics	97	72.4[e]	5	1–5	1–5	3.6 (1.0)	4	13; 2	.83	1.0 (n = 5)
Total	100	74.6[e]	29	5–25	7–25	17.5 (3.5)	18	2; 0	.91	1.0 (n = 5)
Observed measure										
DCM										
Mean WIB Score	333	97.1	1	−5–+5	−2.15–+2.60	0.74 (0.55)	0.89	0; 0	—	0.70 (n = 56)
% WIB +3 or +5	333	97.1	1	0–100	0–80	4.0 (9.0)	0	0; 68	—	0.28 (n = 56)
% BCC Type I	333	97.1	1	0–100	0–100	35.4 (25.6)	30.8	2; 6	—	0.80 (n = 59)
RSOC-QOL										
Agitated behaviors[g]	333	97.1	1	0–100	0–94	11.6 (19.5)	0	0; 56	—	0.90 (n = 54)
Activity level or engagement	333	97.1	1	0–100	0–100	50.5 (25.5)	50.0	2; 2	—	0.77 (n = 54)
Physical contact[g]	333	97.1	1	0–100	0–38	5.6 (7.0)	3.2	0; 32	—	0.81 (n = 54)
PGC-ARS	333	97.1	1	0–100	3–71	33.6 (6.4)	33.3	0; 0	—	0.82 (n = 54)

Notes: For the table, a dash indicates that the task was not done or is not available for the measure.
[a]For completion rate, the denominator is 414 for the measures reported by the care provider, 399 for the measures reported by the resident, and 343 for the resident observation.
[b]Percent of participants scoring at the theoretical maximum and theoretical minimum value for the measure.
[c]Cronbach's alpha.
[d]Intraclass correlation coefficient (Shrout & Fleiss, 1979).
[e]Due to protocols of the instruments and/or of the project, which restricted administration of resident–respondent instruments to persons with scores of ≥10 on the Mini-Mental State Examination (MMSE), only 134 participants (33.6 % of the total sample) were administered the resident instruments. Reported completion rates are only for those residents who met the MMSE criterion and were offered the instrument.
[f]CP–resident subset = the care-provider ratings of the subset of participants for whom resident ratings of the same instrument were collected.
[g]Percent of observations in which the behavior occurred.

Table 3. Correlations (Pearson r) Among Dementia Quality-of-Life Measures Reported by Staff Care Providers

| Measure | QOL-D (Albert) | | | QOL-AD (Logsdon) | ADRQL (Rabins) | | | | | |
	Activities	Positive Affect	Negative Affect		SI	AS	FM	EA	RS	Total
QOL-D (Albert)										
Activities	1									
Positive affect	0.33	1								
Negative affect	−0.09	−0.17	1							
QOL-AD (Logsdon)	0.52	0.46	−0.36	1						
ADRQL (Rabins)										
SI	0.38	0.48	−0.33	0.52	1					
AS	0.38	0.38	−0.18	0.57	0.50	1				
FM	0.24	0.37	−0.65	0.51	0.55	0.31	1			
EA	0.44	0.40	−0.25	0.51	0.50	0.40	0.44	1		
RS	0.18	0.27	−0.45	0.34	0.27	0.21	0.49	0.28	1	
Total	0.44	0.53	−0.54	0.68	0.81	0.67	0.83	0.68	0.57	1

Notes: SI = social interaction; AS = awareness of self; FM = feelings and mood; EA = enjoyment of activities; RS = response to surroundings. For the table, $n = 374$–413; sample size varies because of missing data.

sample size, however, these results should be interpreted with caution.

Discussion

The analyses reported in this article indicate that many instruments are now available to evaluate quality of life among persons with Alzheimer's disease and related dementias that can be successfully used in long-term care populations and have relatively robust psychometric properties. As is clear from the analyses in Table 2, most of the instruments studied, including their component subscales, demonstrated good to excellent interrater reliability and adequate dispersion. Furthermore, the fact that the resident factors of cognition, ADL impairment, depression, agitated behaviors, and pain explained no more than 27% of the variance in any of the measures (Table 9) suggests that these measures are capturing far more than can be inferred from basic information on resident characteristics.

The issue of validity remains a challenge. As was noted by Patrick and Erickson (1993), quality of life is

based largely on theory and values, not on scientific inference. Because theories and values vary as to which elements are most important to quality of life, it is not surprising that different instruments tend to evaluate somewhat different domains and to differ in their scope (Table 1). A few investigators have attempted to empirically determine which domains of quality of life are most highly valued by persons with Alzheimer's disease and/or long-term care residents (Cohn & Sugar, 1991; Kane et al., 2003; Rabins et al., 2000). However, as was demonstrated by Cohn and Sugar, the answers to such questions differ markedly depending on whom you ask. This tendency for different data sources to provide different answers is echoed in our data, most dramatically by the QOL-AD—one of the more comprehensive quality-of-life scales, for which the correlation between resident and caregiver ratings was .02. Prior studies have suggested that correlations between patient and provider ratings tend to be mild to moderate; for example, Logsdon and colleagues (2000) reported a correlation of .40 between resident and provider versions of the QOL-

Table 4. Correlations (Pearson r) Among Dementia Quality-of-Life Measures Reported by Residents

| Measure | QOL-D (Albert) Activities | QOL-AD (Logsdon) | DQoL (Brod) | | | | | |
			Self-esteem	Positive Affect	Negative Affect	Feeling of Belonging	Aesthetics	Total
QOL-D (Albert) activities	1							
QOL-AD (Logsdon)	0.36	1						
DQoL (Brod)								
Self-esteem	0.47	0.70	1					
Positive affect or humor	0.54	0.69	0.74	1				
Negative affect	0.11	0.48	0.42	0.41	1			
Feeling of belonging	0.46	0.63	0.61	0.73	0.20	1		
Aesthetics	0.39	0.47	0.39	0.45	0.12	0.45	1	
Total	0.54	0.78	0.84	0.88	0.55	0.80	0.67	1

Notes: For the table, $n = 93$–120; sample size varies because of missing data.

Table 5. Correlations (Pearson r) Between Dementia Quality-of-Life Measures Reported by Staff Care Providers and Residents

Measure Reported by Care Providers	Measures Reported by Residents							
	QOL-D (Albert) Activities	QOL-AD (Logsdon)	DQoL (Brod)					
			Self-esteem	Positive Affect	Negative Affect	Feeling of Belonging	Aesthetics	Total
QOL-D (Albert)								
Activities	0.24	0.18	0.09	0.20	0.08	0.14	0.19	0.20
Positive affect	0.19	0.07	0.11	0.21	0.03	0.27	0.16	0.20
Negative affect	−0.09	−0.03	-0.02	0.01	−0.26	0.11	0.01	−0.05
QOL-AD (Logsdon)	0.24	0.02	0.04	0.18	0.06	0.17	0.07	0.14
ADRQL (Rabins)								
Social interaction	0.10	0.09	0.07	0.17	0.05	0.15	0.16	0.19
Awareness of self	0.13	0.03	0.23	0.18	0.03	0.32	0.15	0.27
Feelings and mood	0.03	0.06	0.05	0.12	0.21	0.10	0.11	0.17
Enjoyment of activities	0.31	0.20	0.17	0.23	0.01	0.21	0.24	0.23
Response to surroundings	0.18	0.08	0.11	0.17	0.25	0.16	0.12	0.22
Total	0.19	0.12	0.18	0.25	0.17	0.26	0.20	0.30

Notes: For the table, $n = 84$–117; sample size varies because of missing data.

AD, and Thorgrimsen and colleagues (2003) reported a correlation of .69 between resident scores on the QOL-AD and staff scores on the DQoL. While more study is clearly needed on the degree and causes of nonagreement between residents and caregivers, findings from a study of schizophrenics suggest that residents' and providers' judgments are least likely to coincide on activity and social aspects of quality of life and more likely to agree on function and symptom-related domains (Sainfort, Becker, & Diamond, 1996).

A logical solution to the dilemma of validity might be to consider the resident's own opinion to be the "gold standard" (Brod et al., 2000). Unfortunately, study results suggest that the majority of residents with Alzheimer's disease in long-term care have cognitive decline so severe that they may be unable to be administered measures of quality of life. In our stratified random sample, the majority of whom were from RC/AL facilities, between 70% and 76% of participants failed cognitive screening criteria and,

therefore, were not administered the resident measures. Quite possibly, some of these individuals could have provided at least some data; according to Thorgrimsen and colleagues (2003) and Logsdon, Gibbons, McCurry, & Teri (2002), MMSE scores between 3 and 10 define a gray zone in which some individuals can complete quality-of-life measures and others cannot. Similarly, Mozley and colleagues (1999), in conducting in-depth quality-of-life interviews of long-term care residents with dementia, concluded that an MMSE cutoff of 9–10 defined "interviewability" but that some respondents with even lower scores might have been interviewable. When and how to best elicit self-reported quality-of-life data from persons with severe cognitive impairment is a critical one for current practice (Schnelle, 2003), and one for which further research is needed.

Do observational measures provide a superior alternative to proxy measures? While direct observation has theoretical advantages, the state of

Table 6. Correlations (Pearson r) Among Directly Observed Dementia Quality-of-Life Measures

Measure	DCM			RSOC			
	WIB Mean	% WIB +3 or +5	% BCC Type I	% Any Agitation	% Physical Contact	Activity or Engagement	PGC-ARS[a]
DCM							
Mean WIB	1						
% WIB +3 or +5	0.49	1					
% BCC Type I	0.39	0.12	1				
RSOC							
% any agitation	−0.23	−0.07	−0.16	1			
% physical contact	0.00	0.00	0.10	0.17	1		
Activity or engagement	0.44	0.33	0.49	0.19	0.07	1	
PGC-ARS	0.52	0.58	0.15	−0.34	−0.15	0.21	1

Notes: WIB = well- and ill-being score; BCC = behavior category code. For the table, $n = 333$.

Table 7. Correlations (Pearson r) Between Dementia Quality-of-Life Measures Reported by Staff Care Providers and Those Directly Observed

Measure Reported by Care Providers	Dementia Care Mapping			Resident-Staff Observation Checklist			
	WIB Mean	% of WIB +3 or +5	% BCC Type I	% Any Agitation	% Physical Contact	Activity or Engagement	PGC-ARS
QOL-D (Albert)							
Activities	0.25	0.17	0.32	−0.12	−0.03	0.25	0.23
Positive affect	0.30	0.12	0.20	−0.20	0.03	0.19	0.20
Negative affect	−0.09	0.02	−0.18	0.23	0.10	−0.03	−0.16
QOL-AD (Logsdon)	0.33	0.17	0.25	−0.16	−0.18	0.30	0.26
ADRQL (Rabins)							
Social interaction	0.33	0.17	0.32	−0.34	−0.09	0.21	0.25
Awareness of self	0.33	0.16	0.22	−0.19	−0.13	0.30	0.21
Feelings and mood	0.20	0.08	0.23	−0.29	−0.08	0.06	0.22
Enjoyment of activities	0.28	0.08	0.29	−0.16	−0.03	0.25	0.20
Response to surroundings	0.10	−0.02	0.19	−0.13	−0.03	0.02	0.14
Total	0.35	0.14	0.35	−0.33	−0.11	0.23	0.29

Notes: WIB = well- and ill-being score; BCC = behavior category codes. For the table, $n = 302–327$; sample size varies because of missing data.

development of observational instruments is much more primitive than that of proxy-report measures. As is clear from Tables 1 and 2, the observational instruments studied had numerous disadvantages. These include floor effects (agitated behavior and physical contact), lack of variation (WIB scores), poor interrater reliability (the percentage of WIB scores of +3 or +5), and lack of multidimensionality (all measures). Furthermore, the fact that the observational measures tended to correlate more strongly with care-provider-report measures (Table 7) than with resident-report measures (Table 8) suggests that observation may carry with it many of the same inherent biases of proxy reports.

In conclusion, it appears that, while many measures now exist that provide windows to the quality of life of long-term care resident with dementia, no single instrument can claim superiority, and, indeed, no instrument adequately captures the broad canvas of quality of life. Certainly, the science is improving, yet the field is still underdeveloped. One direction that needs to be explored is the use of multiple instruments and sources, to better understand the experiences of persons with dementia (Lawton, 1997). Another is the individualization of assessment, based on the individual and family's values, experiences, and expressed wishes. Given the progressive, terminal nature of Alzheimer's disease, being able to capture a clearer image of quality of life throughout the illness will help guide treatment and,

Table 8. Correlations (Pearson r) Between Dementia Quality-of-Life Measures Reported by Residents and Those Directly Observed

Measure Reported by Residents	Dementia Care Mapping			Resident-Staff Observation Checklist			
	WIB Mean	% WIB +3 or +5	% BCC Type I	% Any Agitation	% Physical Contact	Activity or Engagement	PGC-ARS
QOL-D (Albert) activities	0.13	0.09	0.00	0.26	0.08	0.03	0.14
QOL-AD (Logsdon)	0.13	0.12	0.07	0.13	0.07	0.00	0.20
DQoL (Brod)							
Self-esteem	0.22	0.13	0.06	0.03	0.09	0.18	0.19
Positive affect or humor	0.26	0.18	0.17	0.00	0.05	0.19	0.26
Negative affect	0.17	0.10	0.12	−0.08	−0.17	0.06	0.23
Feeling of belonging	0.08	0.13	−0.01	0.13	0.06	0.04	0.10
Aesthetics	0.19	0.22	0.14	0.05	0.07	0.24	0.27
Total	0.24	0.21	0.11	0.04	0.02	0.18	0.29

Notes: WIB = well- and ill-being score; BCC = behavior category codes. For the table, $n = 72–88$; sample size varies because of missing data.

Measure	Models With Single-Resident Factors (% of Variance Explained by Resident Factor[s][a])					Model With All 5 Resident Factors
	Cognitive Function	ADLs	Depressive Symptoms	Agitated Behavior	Pain	
Proxy-reported meaure ($n = 246$)						
QOL-D (Albert)						
Activities	9.3***	8.8***	0.6	1.4**	0.8	11.9***
Positive affect	6.3***	2.7*	7.6***	2.8***	0	9.4***
Negative affect	6.0***	4.2*	7.4***	9.4***	0	13.5***
QOL-AD Logsdon	19.8***	21.4***	2.8**	2.0**	0.1	26.8***
ADRQL (Rabins)						
Social interaction	15.4***	13.3***	4.0**	3.5***	0	18.7***
Awareness of self	21.8***	16.0***	0.7	3.1**	0	24.4***
Feelings and mood	8.0***	4.7*	9.7***	10.8***	0	15.6***
Enjoyment of activities	6.1***	7.3	1.3	1.9*	0	8.2***
Response to surroundings	1.5	0	4.7**	7.4***	0	7.4***
Total	18.4***	16.4***	8.5***	10.2***	0	24.8***
Observed measure ($n = 222$)						
Dementia Care Mapping						
Mean WIB Score	8.2***	11.7***	0.2	0.7	0	11.8***
% WIB +3 or +5	0.1	1.8*	0	0	0	0
% BCC Type I	19.3***	7.1**	1.4	2.6	0	18.1***
RSOC-QOL						
% Agitated behaviors	17.0***	8.4***	1.9	11.0***	0.8*	20.9***
Activity level/engagement	9.0***	13.0***	0.6	0	1.0	14.9***
% Physical contact	14.5***	10.6***	0	5.1**	2.4	19.4***
PGC-ARS	7.8***	6.9***	2.7	2.7*	0	9.4**
Resident-reported measures ($n = 78$)						
QOL-D (Albert) Activities	0	0	0	2.3	0	0
QOL-AD (Logsdon)	0	0	0	0	2.3	0
DQOL (Brod)						
Self-esteem	0	0	0.2	0	1.9	0
Positive Affect/Humor	0	0	2.5*	0	0	1.9
Negative Affect	0	3.3	0	1.5	0	1.2
Feeling of Belonging	1.1	0	0	4.0*	0	3.8
Aesthetics	0	0	0	0	0	0
Total	0	0	0	0	0	0

Notes: ADLs = activities of daily living. All regression models are hierarchical linear models with the specified global quality-of-life measure as the dependent variable. For care-provider-reported quality-of-life measures, models included random effects for facility and care provider (nested within facility). For the directly observed measures, models include random effects for facility and observer. For the resident-reported measures, models include a random effect for facility. Sample size is restricted to those with data on all resident factors ($n = 246$ for quality-of-life measures reported by care provider, $n = 222$ for directly observed measures, and $n = 78$ for measures reported by resident). An entry of 0 indicates that the estimate of variance reduction was either very small or negative, the latter occurring occasionally in small samples due to uncertainty in estimation even though a nonnegative estimate was expected.

[a]Variance reduction is the percent decrease in the total variance for the model of interest, when compared with the total variance of the model without fixed effects; total variance is defined as the sum of resident, care provider (or observer), and facility-level variances from the hierarchical linear model.

*$p < .05$; **$p < .01$; ***$p < .001$. Statistical significance is based on T statistics for individual fixed effects in the single-factor models and on an F test for the joint effects of all resident factors in the full model.

ultimately, improve the experience of persons with the disease, their families, and those who provide their care.

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Brief Reports

Characteristics Associated With Depression in Long-Term Care Residents With Dementia

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We describe the prevalence, assessment, and treatment of, as well as characteristics associated with, depression in residential care/assisted living and nursing home residents with dementia. Overall, 25% of the participants were depressed. Depression was related to severe cognitive impairment, behavioral symptoms, pain, and for-profit nursing home residence.

*Key Words: Depression, Assisted living,
Residential care, Nursing homes, Dementia*

Although little research has examined the prevalence and treatment of depression for those with dementia in long-term care settings, especially in residential care/

assisted living (RC/AL), existing data suggest that depressive symptoms are common in this population and associated with poor outcomes. Estimates of the prevalence of clinical depression among elderly nursing home residents range from 9% to 30% (Parmelee, Katz, & Lawton 1989; Payne et al., 2002; Rovner et al., 1991), with high levels of depressive symptomatology in over two thirds of nursing home residents (McCurren, Dowe, Rattle, & Looney, 1999, Ryden et al., 1999). Overall, depression is underdetected (Bagley, et al., 2000; Rovner et al.; Ryden et al.) and undertreated in nursing homes, especially among residents with dementia (Brown, Lapane, & Luisi, 2002).

The one large multistate study of depression in RC/AL facilities (Watson, Garrett, Sloane, Gruber-Baldini, & Zimmerman, 2003) found significant depressive symptomatology among 13% of RC/AL residents, with only 18% of these patients taking antidepressant medication. Depressive symptoms were more than twice as common among RC/AL residents with mild or moderate dementia than among those without dementia, and depressed residents were at greater risk of discharge to nursing home and death.

To our knowledge, few studies in long-term care have compared depression across RC/AL and nursing home settings, specifically for patients with dementia, and none have examined the association between depression and staff perception of depression, treatment, or adequacy of care in these settings. Given the high prevalence of dementia and depression in long-term care, and concern regarding underdetection and undertreatment, predictors of recognition and treatment are important to examine. In this article we examine the prevalence of depression in residents with

dementia in long-term care, and we describe staff and facility characteristics associated with depression and the characteristics of residents with dementia who are depressed.

Methods

Participants

Study participants were part of the Dementia Care project of the Collaborative Studies of Long-Term Care, a four-state stratified sample described elsewhere (see the introduction to this issue and Zimmerman et al., 2001). Potential participants were randomly selected from the group of residents with a diagnosis of dementia who were age 65 years or older residing in 10 nursing homes and 35 RC/AL facilities. The participation rate was 73%. These analyses are limited to the 347 participants (82.4% of the overall sample of 421) with a depression assessment completed by a supervisor. The supervisor was chosen as the informant to obtain a consistent rating from the person with the best clinical insight who was most familiar with the resident. The majority of the supervisors reported good familiarity with the residents (87%) and had known them for 6 months or more (83%). Most (76%) supervisor respondents were registered nurses or licensed practical nurses.

Measures

Depression.—A supervisory staff member rated participants for depression by using items on the Cornell Scale for Depression in Dementia (CSDD; Alexoupoulos, Abrams, Young, & Shamoian, 1988). This modified administration format of the CSDD includes 19 items asking about symptoms over the prior 7 days, each rated on a 3-point scale, with higher scores indicating greater depression (range = 0–38). Scores of 7 or greater indicate symptomatology consistent with clinically significant depression (Alexoupoulos et al.; Vida, Des Rosiers, Carrier, & Gauthier, 1994).

Care Provision.—For each resident, supervisory staff reported whether and how depression was formally assessed (by a mental health professional or by use of a written, standardized instrument) and treated (professional and other nonpharmacological); if detected and treated, how successful treatment was considered to be; and whether depression was perceived to be currently present (see Tables 1 and 2 for coding details). The research staff recorded antidepressant medication use (all regular prescription and nonprescription medications administered at least 4 of the past 7 days) verbatim from the residents' medication administration records and coded the information by using American Hospital Formulary Service system criteria (McEvoy, 2001). The administrator reported depression training as the percentage of supervisory and direct care staff who received formal training in depression assessment and treatment in the past year.

The staff rated perception of training regarding how well trained they felt in depression assessment and treatment. The administrator for the facility answered queries concerning the use of mental health professionals in formal care planning and perceived facility ability to treat depression.

Other Resident Data (Covariates).—Demographic data, including age, gender, and race, was collected from the supervisor. Cognition was assessed with the Mini-Mental State Examination (Folstein, Folstein, & McHugh, 1975) and the Minimum Data Set Cognition Scale (Hartmaier, Sloane, Guess, & Koch, 1994); function with the Minimum Data Set Activities of Daily Living Scale (Morris, Fries, & Morris, 1999); and comorbidity through a list of 10 conditions (excluding mental health diagnoses). The supervisor assessed behavioral symptoms by using the Cohen-Mansfield Agitation Inventory (Cohen-Mansfield, 1986) and pain by using the Philadelphia Geriatric Center Pain Intensity Scale (Parmelee, Katz, & Lawton, 1991). Activity participation was obtained from the care provider report, using the Albert Patient Activity Scale (Albert et al., 1996). Mobility information was obtained from observational data (Williams et al., 2005, this issue). Information regarding food and fluid intake was derived from the Structured Meal Observational instrument (Reed, Zimmerman, Sloane, Williams, & Boustani, 2005, this issue).

Analyses

Descriptive and regression results present bivariate analyses predicting differences in setting (RC/AL vs nursing home) and current levels of depression, using a CSDD cutpoint of ≥ 7. Regression models we fit using generalized estimating equations (Liang & Zeger, 1986) assuming a binomial distribution and logit linking function for the dichotomous outcome of depression and other dichotomous outcomes, and a Gaussian distribution for analyses of setting (RC/AL vs nursing home) on continuous variables. An exchangeable correlation structure was specified to account for clustering within facilities. Odds ratios (ORs) are presented with 95% confidence intervals (CIs). Multivariate regressions (controlling for age, gender, race, cognition, comorbidity, and functional status) examine predictors of current depression; interactions of predictors with setting were also tested. Values of facility predictors were ascribed to all residents within that facility.

Results

The 347 participants (with dementia) in these analyses had an average age of 84.5 ($SD = 7.1$); 81.3% were female, and 10.1% were Black. Most were severely cognitively impaired (60.7%); 13.6% were mildly and 25.7% moderately cognitively impaired.

Depression and Care by Setting.—Table 1 displays

Table 1. Prevalence of Depression and Relevant Components of Care in Dementia Care Study Sample, by Setting

Depression	RC/AL (N = 238) % or M (SD)	Nursing Home (N = 109) % or M (SD)	p^a
Prevalence			
Residents with depression	23.9	26.6	.808
Mean supervisor-rated CSDD score	4.3 (4.3)	4.7 (4.9)	.434
Assessment (in the last year)			
By a mental health professional[b]	32.2	45.3	.275
Using written or standardized assessment	26.4	37.7	.085
Perceived presence, current	14.8	22.6	.126
Treatment			
Treatment by a mental health professional[b]	15.2	26.5	.015
Antidepressant used	36.4	42.1	.344
Nonpharmacologic treatment[c]	33.0	45.1	.146
Perceived success (if perceived depressed; quite a bit or extremely)	54.8	50.8	.780
Reports of formal training attendance and perceived adequacy to detect and treat[d]			
Supervisory staff			
None in facility	23.9	12.6	.189
Some in facility	27.7	32.6	.590
Most in facility ($\geq 75\%$)	48.3	54.7	.291
Direct care providers			
None in facility	42.9	12.6	.099
Some in facility	8.8	10.5	.421
Most in facility ($\geq 75\%$)	48.3	76.8	.237
Facility is adequately able to treat	73.1	89.0	.241
Staff feel adequately trained to assess	78.5	97.2	.092
Staff feel adequately trained to treat	70.9	87.2	.246
Mental health professionals in formal care planning	28.4	77.1	.017

Notes: RC/AL = residential care/assisted living; CSDD = Cornell Scale for Depression in Dementia. Depression is assessed by supervisor report using a modified administration-format version of the CSDD, and refers to ≥ 7 on the 38-point scale. Except as noted for "training," all data are resident level, are of those residents for whom outcome data (i.e., CSDD) are available, and are from supervisor report. Due to missing data, N varies from 208 to 238 (RC/AL) and 95 to 109 (nursing home), except in the case of "perceived success of treatment," which is relevant only for those with depression recognized in the last year, and for whom there are data for 126 (53%) and 61 (56%) residential care and nursing home participants, respectively.

[a] Adjusted for facility-level clustering using generalized estimating equations (GEE; exchangeable correlation matrix); p values are based on score statistics.

[b] Mental health professionals could include psychiatrist, psychologist, mental health social workers, physician, or anyone defined as a professional mental health provider by the supervisor.

[c] Nonpharmacologic treatment is any other reported nonpharmaceutical or treatment not provided by a mental health professional. The most frequently cited examples were other medical care (38%), emotional or social support (32%), and recreational activities (22%).

[d] Data regarding supervisory staff training and direct care provider training ("formal" training, first two sets of items), facility adequacy to treat, and mental health professional involvement are facility level, reported by administrators, and refer to the previous year. Staff feelings of training adequacy are reported by the one supervisor (or direct care provider, if supervisor data are missing) who is most involved in the resident's care; "adequately" is quite or extremely well trained.

the depression prevalence for the 238 RC/AL residents and 109 nursing home residents and relevant components of care. Prevalence was not significantly different between RC/AL and nursing homes; 25% of the residents in these settings (24% in RC–AL, 27% in nursing homes) had CSDD scores consistent with depression. The two most frequent items listed by residents were being anxious (48%) and being easily annoyed (48%), and more than 20% of the overall sample of individuals endorsed items about being sad, not responsive, agitated, having slow movements, and waking many times at night (results not shown). Nursing home participants were more likely to be treated by a mental health professional and to reside in facilities that include mental health professionals in formal care planning than those in RC/AL. We found no other significant differences between nursing homes and RC/AL facilities.

Predictors of Depression. — Table 2 presents both the descriptive distributions by presence of depression and the results of regressions predicting current depression. Among currently depressed participants, 42% had been recognized as depressed by the staff supervisor; 54% were currently on an antidepressant medication. A substantial proportion of those not currently depressed were also on antidepressants (33%). Only 28% of participants with current depression had any formal mental health treatment.

Participants with depression were more likely to be severely or very severely cognitively impaired, display behavioral symptoms, and be in pain than those who were not depressed. In the unadjusted (but not in the adjusted) model, depressed participants were more likely to have low activity. Residents in for-profit facilities were more likely to be depressed. Treatment (professional, nonpharmacologic, and antidepressant

Table 2. Characteristics Associated With Depression, Unadjusted and Adjusted

| Characteristic | Distribution of Characteristics as % or M (SD) Depressed | | Relationship Between Characteristic and Presence of Depression | | | |
	No (n = 252)	Yes (n = 76)	Unadjusted OR	95% CI	Adjusted[a] OR	95% CI
Resident[b]						
Cognitive status						
Mildly impaired	15.9	3.9	1.00	—	1.00	—
Moderately impaired	29.4	15.8	2.19	(0.73, 6.58)	1.94	(0.69, 5.42)
Severely impaired	23.4	27.6	4.68	(1.65, 13.29)	4.03	(1.45, 11.22)
Very severely impaired	31.3	52.6	6.81	(2.45, 18.91)	5.46	(1.93, 15.43)
Behavioral symptoms[c]	50.0	84.2	5.20	(2.73, 9.88)	4.80	(2.51, 9.19)
Low activity	44.8	51.3	1.62	(1.07, 2.47)	1.39	(0.88, 2.21)
High pain	15.7	36.8	2.68	(1.36, 5.29)	3.54	(1.59, 7.85)
Immobile	12.4	11.5	0.93	(0.44, 1.98)	0.93	(0.42, 2.07)
Low food intake	53.2	50.7	0.96	(0.63, 1.44)	0.87	(0.55, 1.38)
Low fluid intake	48.6	54.9	1.40	(0.90, 2.16)	1.26	(0.79, 2.02)
Facility[d]						
Facility type						
Nursing home	31.3	36.8	1.00	—	1.00	—
RC/AL						
< 16 beds	13.1	17.1	1.01	(0.42, 2.43)	1.28	(0.46, 3.58)
Traditional	23.4	22.4	0.62	(0.21, 1.87)	1.05	(0.27, 4.12)
New-model	32.1	23.6	0.59	(0.25, 1.39)	0.71	(0.27, 1.84)
Facility size (OR per 10 beds)	87.3 (54.7)	77.0 (48.8)	0.97	(0.91, 1.03)	0.96	(0.90, 1.03)
For-profit ownership[c]	67.9	82.9	2.23	(1.19, 4.16)	2.53	(1.29, 4.98)
Assessment of depression						
Professional mental health assessment	34.3	43.8	1.62	(0.94, 2.8)	1.75	(0.97, 3.17)
Written or standardized assessment	28.0	39.7	1.68	(0.94, 3.02)	1.89	(0.99, 3.61)
Perceived presence, current	7.6	41.9	7.69	(4.42, 13.39)	7.48	(3.96, 14.14)
Treatment of depression						
Treatment by a mental health professional	16.3	28.4	1.96	(1.07, 3.58)	2.10	(1.10, 4.02)
Antidepressant used	33.3	54.3	2.23	(1.27, 3.92)	2.50	(1.33, 4.70)
Nonpharmacologic treatment	30.3	58.3	2.79	(1.66, 4.69)	3.69	(2.07, 6.56)
Perceived success (if perceived depressed)	61.7	48.3	0.58	(0.29, 1.13)	0.73	(0.37, 1.43)
Reports of formal training attendance and perceived adequacy to detect and treat depression						
% of supervisory staff trained						
None in facility	21.2	21.9	1.00	—	1.00	—
Some in facility (1–74%)	34.4	17.8	0.50	(0.15, 1.66)	0.50	(0.13, 1.94)
Most in facility (≥ 75%)	44.4	60.3	1.43	(0.72, 2.82)	1.36	(0.60, 2.61)
% of direct care providers trained						
None in facility	38.6	26.0	1.00	—	1.00	—
Some in facility (1–74%)	9.5	9.6	1.47	(0.61, 3.55)	1.25	(0.49, 3.18)
Most in facility (≥ 75%)	51.9	64.4	1.75	(0.83, 3.66)	1.58	(0.71, 3.53)
Facility is adequately able to treat	75.4	82.9	1.33	(0.63, 2.81)	1.32	(0.59, 2.96)
Staff feels adequately trained to						
Assess	82.1	88.2	1.80	(0.72, 4.47)	1.55	(0.53, 4.52)
Treat	76.1	69.7	0.75	(0.31, 1.78)	0.71	(0.29, 1.73)
Mental health professionals in care planning	46.4	36.8	0.67	(0.34, 1.31)	0.62	(0.29, 1.32)

Notes: RC/AL = residential care–assisted living. Depression was assessed by supervisor report using a modified administration-format version of the Cornell Scale for Depression in Dementia (CSDD) and refers to ≥ 7 on the 38-point scale. Except as noted for "training," all data were resident level, were of those residents for whom outcome data (i.e, CSDD) and supervisor data (required for adjustment) were available, and were from supervisor report. Models were restricted to those participants with all the covariates used in adjusted models; only 19 participants were removed from the unadjusted analyses due to missing covariates. Due to missing data in the predicted variables, N varied from 270 to 328 in all models, except in the case of "perceived success of treatment," which was relevant only for those where the staff detected depression (n = 86).

[a]Adjusted for male gender, non-White race, age, cognitive status, number of 10 comorbidities (congestive heart failure; high blood pressure or hypertension; myocardial infarction, heart attack, angina, arrhythmias, or other heart problem; diabetes; kidney disease or renal insufficiency; arthritis, rheumatism, degenerative joint disease, lupus, erythematosis, or scleroderma; fractured bones or osteoporosis; cerebrovascular disease, stroke, TIA, or CVA; hemiplegia or paraplegia; asthma, emphysema, bronchitis, or COPD), and impairments in 7 activities of daily living (bed mobility, transfer, locomotion, dressing, eating, toilet use, hygiene).

[b]Cognitive status was based on Mini-Mental State Examination (MMSE) or Minimum Data Set–Congition (MDS-COGS) scores, if the MMSE is missing (n = 52). Cutpoints for mild, moderate, severe, and very severe (MMSE) are ≥ 18, 11–17, 3–10, and 0–2, respectively. MDS-COGS cutpoints are 0–1, 2–4, 5–8, and 9–10, respectively. Behavioral symptoms were any behavior exhibited weekly on the Cohen-Mansfield Agitation Inventory. Low activity was < 9 (median) on the Albert Patient Activity Scale. Pain was ≥ 2 on a modified administration-format version of the Philadelphia Geriatric Center–Pain Intensity Scale. Immobile was no change in location or position during 3 hours of observation. Low food and fluid intake was ate ≤ 3/4 of meal or drank ≤ 8 ounces on the Structured Meal Observation. Behavioral symptoms and pain were from supervisor report; activity was from care provider report; and immobility and consumption were based on direct observation.

[c]There was an effect modification for the type of long-term-care facility (nursing homes vs RC/AL) in the association between depression and behavioral symptoms and between depression and for-profit ownership. See text for details.

[d]Data regarding supervisory staff training and direct care provider training (first two sets of items), facility adequacy to treat, and mental health professional involvement were facility level and reported by administrators. Staff feelings of training adequacy were reported by the one supervisor (or direct care provider, if supervisor data are missing) who was most involved in the resident's care; "adequately" is quite or extremely well trained.

medication) was more common among those with depressive symptoms, as was staff perception of current depression. Depression was lower for those whom staff perceived success in treatment.

Behavioral symptoms and for-profit ownership showed statistically significant interactions with facility type (RC/AL vs nursing home). For behavioral symptoms, the association with depression was much stronger (OR = 7.33, 95% CI = 3.04–17.68) in RC/AL than in nursing homes (OR = 2.78, 95% CI = 1.38–5.58; interaction p = .030). Conversely, the association of depression with for-profit status was stronger in nursing homes (OR = 9.62, 95% CI = 3.65–25.35) than in RC/AL facilities (OR = 1.22, 95% CI = 0.61–2.47; interaction p = .001).

Discussion

Findings of this study document the high prevalence of depressive symptomatology among those with dementia in long-term care. Overall, 24% of RC/AL and 27% of nursing home participants in this sample had CSDD scores of 7 or greater. Use of mental health professionals in treatment and formal care planning were the only significant differences in care that we observed between nursing homes and RC/AL, and professional treatment was higher among those participants with current depression. Overall, however, the involvement of mental health professionals in the assessment and treatment of depression in both nursing homes and RC/AL facilities is low (< 50%). Depression was more common among participants with severe dementia, behavioral symptoms, and those with pain. The correlation with behavioral symptoms was stronger in RC/AL facilities than in nursing homes.

Depression was more common for participants in for-profit nursing homes than for those in nonprofit homes and all RC/AL facilities. For-profit status in nursing homes has been found to be associated with more deficiencies (Harrington, Zimmerman, Karon, Robinson, & Beutel, 2000) and lower nurse staffing hours (Harrington & Swan, 2003). To our knowledge, an association between profit status and care in RC/AL has not been documented, and the meaning of for-profit status may differ across facility types.

Among six key domains of care, depression was the quality-of-life domain with the lowest perceived treatment success and staff rating of training adequacy (see introduction to this issue), although it is less common than behavioral symptoms, low activity, and low food and fluid intake. Also, the percent of participants who reside in facilities with no training provided for supervisors (21%) or care providers (35%), on depression was higher than lack of training for the other quality domains examined. However, level of training or perceived ability to assess or treat was unrelated to actual depression in these analyses and was surprisingly high. Admittedly, the percentage of staff with formal training in depression care was not validated, and the content of training was not specified. It is unclear why these staff members feel very well equipped to treat and assess depression, when de-

pression is not easily treated and staff themselves report success in only 48% of the identified cases. Other studies in nursing home settings (not limited to dementia patients) have found very low rates of training for depression (Bagley et al., 2000), and, even when training is considered mandatory, there is poor compliance and the impact of knowledge beyond 1 month is minimal (Brooks, Renvall, Bulow, & Ramsdell, 2000; Cohen-Mansfield, Werner, Culpepper, & Barkley, 1997). Furthermore, although the perceived presence of depression was related to higher prevalence, it is worth noting that over one half of the participants with depression were undetected by staff.

About 54% of depressed and 33% of nondepressed participants were taking antidepressant medications, and the use of antidepressants was more prevalent among those who were depressed than other formal mental health treatments. Dose, frequency, and indication information about the medications was not recorded, and so we cannot determine the adequacy of treatment. A large portion of the 33% (those taking medications among nondepressed individuals) may indicate treatment success, but we cannot exclude the possibility of inappropriate use of these medications.

Some caveats are in order. The CSDD is a measure of depressive symptoms, not a clinical diagnosis, and caution should be used when the results are compared with more clinical studies. However, the use of the CSDD as a screening tool for patients with dementia has been advocated in a recent practice guideline (American Geriatrics Society & American Association for Geriatric Psychiatry, 2003), and its utility in predicting nursing home discharge and death in RC/AL settings is established (Payne et al., 2002; Watson et al, 2003). Typically, the CSDD is rated by a clinician after data are gathered through observation and caregiver interview. In this study, the nursing supervisor rated the CSDD items, for a number of reasons: (a) inability of moderately or severely demented patients to respond; (b) the four-state sample of individuals that precluded sending psychiatrists to all facilities; (c) lack of family proxies for many of residents; (d) potential differences in staffing (and availability of staff) across assisted living and nursing home facilities; and (e) 87% of supervisors reported high familiarity with the resident. Using a nursing supervisor established a consistent, clinically oriented respondent across the sites, but it would have been ideal to obtain depression information from multiple respondents. Thus, the CSDD rating likely provides an underestimate of the true prevalence of depression symptoms. Further, because CSDD ratings were provided by the same staff member who rated current detection and treatment, the degree of correspondence between these measures may be higher as a result of similar biases in underrecognition of depression and depression symptoms. Finally, the sample of individuals is not representative and so generalizability is limited.

Despite these limitations, this study suggests that undetected depression among residents with dementia is high in both long-term-care settings, particularly in for-profit nursing homes. The role of improved de-

pression training and involvement of mental health professionals in long-term care should be further investigated.

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Characteristics Associated With Behavioral Symptoms Related to Dementia in Long-Term Care Residents

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This article describes care for behavioral symptoms related to dementia (BSRD) and identifies their potential correlates among 347 residents with dementia living in 45 assisted living facilities and nursing homes from four states. The prevalence of BSRD was associated with staff training and resident cognition, mood, mobility, and psychotropic use. Attention to staff training and depression management might improve BSRD.

Key Words: Agitation, Assisted Living, Residential Care, Nursing Homes

Behavioral symptoms related to dementia (BSRD) are defined as verbal, vocal, or motor activities that are considered to be aggressive, excessive, or lack adherence to social standards. BSRD are prominent factors in the decision to seek long-term residential placement, can lead to inadequate management of health conditions, and constitute a common stressor resulting in staff burnout and turnover in institutional settings (Cohen-Mansfield, 2001). Depending on the measurement and the setting, the prevalence of BSRD in long-term care, including nursing homes and residential care/assisted living (RC/AL) facilities, varies from 40% to 90% (Brodaty, et al, 2001; Gruber-Baldini, Boustani, Zimmerman, & Sloane, 2004).

BSRD result from an interplay between host (resident), agent (caregiver), and environmental (setting) factors (Cohen-Mansfield, 2001). The majority of studies have evaluated only host characteristics and identified increased age, being male, functional impairment, moderate to severe cognitive deficit, greater comorbidity, pain, psychosis, and depressed mood as potential precipitants for BSRD (Brodaty, et al, 2001; Cohen-Mansfield, 2001; Gruber-Baldini et al, 2004). Evidence for caregiver and environmental factors is scattered (Roth, Stevens, Burgio, & Burgio, 2002; Sloane, Mitchell, Preisser, et al., 1998). This study begins to shed light on the relationship of caregiver and environmental factors to BSRD. We first describe the provision of care for behavioral symptoms for RC/AL and nursing home residents with dementia, such as care-provider assessment and management of symptoms. Second, we identify potential environmental and caregiver characteristics that play a role in BSRD, independent of the resident's cognitive and functional status.

Methods

Sample

The Dementia Care project randomly selected 421 residents 65 years or older who had a diagnosis of dementia and were living in a sample of 35 RC/AL facilities and 10 nursing home in Florida, Maryland, New Jersey, and North Carolina; of these, 347 had

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a measurement of their BSRD and were included in these analyses. There were no significant differences in cognition between the residents with and without an assessment of BSRD. Details about the Dementia Care project and data collection procedures can be found elsewhere (Zimmerman, Sloane, Heck, Maslow, & Schulz, 2005, this issue).

Measures

The Dementia Care project assessed BSRD with the short form of the Cohen-Mansfield Agitation Inventory (CMAI), which has adequate validity and reliability (Cohen-Mansfield, 1995). The 14-item CMAI identifies the frequency (on a 5-point scale) of behavior symptoms during the previous 2 weeks based on interviews with the supervisor familiar with the resident. The CMAI includes three subtypes of behaviors: aggressive (4 items), physically nonaggressive (5 items), and verbal (5 items). A frequency of at least once a week on any of the 14 items was used to indicate the presence of behavioral symptoms. The CMAI is one of the most commonly used instruments to measure BSRD in epidemiological studies.

BSRD care provision.—For each resident, the supervisor also reported whether BSRD were perceived to be currently present (her or his own perception of a moderate level of BSRD), how BSRD were assessed and treated, and, if detected, how successful treatment was considered to be.

Resident demographics (age, gender, race, and presence of 11 comorbid medical conditions) and facility information (facility type, size, and profit status) were collected through interviews with the supervisor and the administrator. Cognitive status was based on the Mini-Mental State Examination (MMSE) via interviews with the resident (Folstein, Folstein, & McHugh, 1975) or the Minimum Data Set Cognition Scale (MDS-COGS) via interviews with the supervisor (Hartmaier, Sloane, Guess, & Koch, 1994), if the MMSE was unavailable ($N = 51$). MMSE cutpoints for mild, moderate, severe, and very severe were ≥ 18, 11–17, 3–10, and 0–2; respective MDS-COGS cutpoints were 0–1, 2–3, 5–8, and 9–10. Depression, functional status, and pain were assessed by interviews with the supervisor using the Cornell Scale for Depression in Dementia (CSD-D; Alexopoulos, 1988), the Minimum Data Set Activity of Daily Living scale (MDS-ADL; Morris, Fries, & Morris, 1999), and the Philadelphia Geriatric Center Pain Intensity Scale (Parmelee, 1994). Care providers assessed activity involvement with the Albert Patient Activity scale (Albert et al., 1996). Mobility and food and fluid intake were measured via direct observation (Williams et al., 2005, this issue) and the Structured Meal Observation (Reed, Zimmerman, Sloane, Williams, & Boustani, 2005, this issue). Medication use (all regular prescription and nonprescription medications administered at least 4 of the past 7 days) was recorded from residents' medication records and coded using American Hospital Formulary Service system criteria (McEvoy, 2001). Medications included neuroleptics, antidepressants, hypnotics, and cholinesterase inhibitors (ChEIs). Care provider characteristics, including dementia-sensitive attitudes toward residents, work stress, and satisfaction working with this population were assessed by interviews with the care provider using the Approaches to Dementia Care scale (Lintern, Woods, & Phair, 2000), the Work Stressors Inventory (Schaefer & Moos, 1996) and the Staff Satisfaction scale (Åström, Nilsson, Norberg, & Winblad, 1990). The physical environment was assessed using the Special Care Unit Environmental Quality Scale (SCUEQS) and the Assisted Living Environmental Quality Scale (ALEQS; Sloane et al., 2002).

Analyses

We computed simple descriptive statistics separately for RC/AL and nursing homes. We did statistical comparison of these characteristics based on score statistic p values from generalized estimating equations (GEE; Diggle, Heagerty, Liang, & Zeger, 2002) applied to linear or logistic models and an exchangeable correlation structure, with facilities specified as clusters. Similarly, we computed descriptive statistics for those for whom the supervisor reported BSRD compared to those with no BSRD. We estimated odds ratios and 95% confidence intervals using separate binary logistic regression models for each characteristic, controlling for clustering using GEE empirical standard error estimates and exchangeable correlation. We estimated adjusted odds ratios, controlling for resident age in years, gender, non-White race, cognitive impairment, comorbidity, and functional status. Finally, to ensure that the factors associated with supervisor report of BSRD did not differ between nursing homes and RC/AL facilities, we tested a setting-by-characteristic interaction term in each multivariable logistic regression model.

Results

Caring for Residents With BSRD in Long-Term Care.—The mean age of the study subjects was 84.5 ($SD = 7.1$); 18% were male, 10% were non-White, and the majority were severely cognitively impaired (14% had mild, 26% had moderate, 24% had severe, and 37% had very severe cognitive deficit). As shown in Table 1, using supervisor ratings of 1 or more BSRD occurring at least weekly within the past 2 weeks (based on the CMAI), 56% of RC/AL residents and 66% of those living in nursing homes had BSRD. We obtained a similar prevalence when supervisors were asked their perception as to whether residents had BSRD in the past 2 weeks. A majority of residents in both settings had been assessed for BSRD in the last year. However, over the past year, a physician, nurse, or a mental health professional treated 49% of RC/AL residents for BSRD, compared to 71% of those in nursing homes ($p = .014$). Among all residents, 19% to 36% were receiving at least one neuroleptic, antidepressant, or hypnotic, with no statistical differences between settings. A higher

percentage of RC/AL residents received ChEIs than those residing in nursing homes (35% vs 19%, $p = .015$). Finally, two thirds of both RC/AL and nursing home residents with BSRD were considered by the facility supervisors to have successfully managed BSRD.

The reported training for BSRD detection and management was high in both RC/AL and nursing homes, and supervisors and care providers in both settings perceived themselves as being well trained in assessing and treating BSRD. Care provider attitudes toward caring for dementia residents and satisfaction did not differ between nursing home and RC/AL settings, although care provider stress was higher in nursing homes than in RC/AL ($p = .047$). Finally, there was a difference between the environments of the two settings as measured by the SCUEQS and ALEQS, with RC/AL scoring higher.

Characteristics Associated With BSRD in Long-Term Care.—As shown in Table 2, BSRD were more common among those with more cognitive impairment and with depression but less common among immobile residents; also, BSRD were associated with pain in nursing homes only. The odds of having BSRD did not differ by facility type, size, or ownership but were higher when residents were assessed by professionals or with standardized measures and were being treated for BSRD. Examining the relationship between staff training and BSRD, residents living in facilities with a higher percentage of supervisors trained in treating and managing BSRD were less likely to display BSRD (OR 0.28; 95% CI 0.15–0.53), but the odds of having BSRD were significantly elevated for residents whose most involved staff felt adequately trained to assess BSRD (OR 2.63; 95% CI 1.14, 6.04). Finally, in evaluating the care provider characteristics that might impact BSRD, our study found that staff sensitive attitudes toward dementia care (Lintern Approaches to Dementia Care scale), staff work stress (Schaefer Work Stressors Inventory), and staff satisfaction (Åström Satisfaction scale) were not related to the prevalence of BSRD.

Discussion

Despite high reporting of assessment, management, and training, BSRD are still very common (56% to 66%) among long-term care residents with dementia, with similar percentages of residents using neuroleptics, antidepressants, and hypnotic in nursing homes and RC/AL facilities. Some interesting differences between nursing homes and RC/AL facilities were the greater use of ChEIs (the current standard of care for Alzheimer's disease pharmacological treatment) in RC/AL facilities and the higher use of professional services to manage BSRD in nursing homes. These variations might be expected, as the percentage of residents with mild to moderate dementia (the indicated stage for drug treatment and the stage with less BSRD) is higher in RC/AL facilities (Gruber-Baldini

Table 1. Prevalence of Behavioral Symptoms and Relevant Components of Care in Dementia Care Study Sample, by Setting

Variable	RC/AL ($n = 238$) % or M (SD)	NH ($n = 109$) % or M (SD)	p
Prevalence of BSRD			
Residents with BSRD	56.3%	66.1%	.133
Assessment of BSRD			
Professional	59.4%	73.3%	.436
Written or standardized	43.4%	59%	.083
Perceived presence, current	57.4%	66.4%	.215
Treatment of BSRD			
Professional	48.6%	71.3%	.014
Informal	60.2%	72.2%	.155
Receiving neuroleptics	36%	35.5%	.898
Receiving antidepressant	36.4%	42.1%	.353
Receiving hypnotics	21.8%	18.7%	.626
Receiving Cholinesterase inhibitors	35.1%	18.7%	.015
Perceived success (if perceived agitated)	64.5%	64.9%	.437
Training to detect and treat BSRD[a]			
Supervisory staff			
None in facility	4.4%	0%	.724
Some in facility	19.3%	31.2%	
Most in facility ($\geq 75\%$)	76.3%	68.8%	
Direct care providers			
None in facility	7.5%	0%	.392
Some in facility	16.2%	19.3%	
Most in facility ($\geq 75\%$)	76.3%	80.7%	
Staff feels adequately trained to assess	96.6%	88.1%	.558
Staff feels adequately trained to treat	94.5%	82.6%	.124
Staff approach to dementia care	75 (6.9)	75.6 (6.4)	.413
Staff work stress	1.7 (0.4)	2.0 (0.7)	.047
Staff satisfaction	63.1 (9.9)	60.8 (10.8)	.453
Environment			
SCUEQS	25.2 (5.0)	20.5 (2.9)	.002
ALEQS	13.7 (4.1)	10.9 (2.3)	.034

Notes: RC/AL = residential care/assisted living; NH = nursing home; BSRD = behavioral symptoms related to dementia; SCUEQS = Special Care Unit Environment Quality Scale; ALEQS = Assisted Living Environmental Quality Scale. For the table, behavioral symptoms are assessed by supervisor report on the Cohen Mansfield Agitation Inventory and refer to one or more behaviors that occurred at least weekly. P values are based on score statistics and are adjusted for facility-level clustering by general estimating equations (exchangeable correlation matrix). Except as noted for training, all data are resident level, are of those residents for whom outcome data are available, and are from supervisor report. Due to missing data, *n* varies from 219 to 238 (RC/AL) and 105 to 109 (NH), except in the case of perceived success of treatment, which is relevant only for those with BSRD and for whom there are data for 197 (83%) and 97 (89%) RC/AL and NH subjects, respectively.

[a]Data regarding supervisory staff training and direct care provider training are facility level and reported by administrators. Staff feelings of training adequacy are reported by the one supervisor (or direct care provider, if supervisor data are missing) who is most involved in the resident's care; adequately is quite or extremely well trained.

et al, 2004). However, after adjusting for resident characteristics (age, gender, race, cognition, comorbid-

Table 2. Characteristics Associated With Behavioral Symptoms, Unadjusted and Adjusted

| Characteristic | Distribution of Characteristic as % or M (SD) | | Relationship Between Characteristic and Presence of BSRD | |
	No BSRD	BSRD	Unadjusted OR (95% CI)	Adjusted[a] OR (95% CI)
Resident[b]				
Cognitive status				
Mildly impaired	24.6%	4.7%	1.0 —	1.0 —
Moderately impaired	26.8%	25.8%	5.17 (2–13.39)	5.46 (2.08–14.29)
Severely impaired	25.4%	23.7%	4.89 (2.02–11.83)	5.04 (2.07–12.28)
Very severely impaired	23.2%	45.8%	9.46 (3.44–26)	8.9 (3.07–25.84)
Depressed	8.7%	33.7%	4.99 (2.62–9.49)	4.57 (2.31–9.06)
Low activity	41.5%	49.7%	1.67 (1.11–2.52)	1.34 (0.83–2.18)
High pain[c]				
NH	32%	19%	0.40 (0.19–0.84)	0.39 (0.19–0.76)
RC/AL	13%	24%	1.86 (0.79–4.37)	2.14 (0.80–5.75)
Immobile	17.1%	8.8%	0.57 (0.32–1.01)	0.46 (0.24–0.91)
Low food consumption	48.9%	55.4%	1.24 (0.75–2.08)	1.25 (0.71–2.2)
Low fluid consumption	46.6%	2.2%	1.07 (0.67–1.71)	1.01 (0.62–1.64)
Facility				
Facility type				
NH	26.8%	37%	1.0 —	1.0 —
RC/AL, < 16 beds	15.9%	12.6%	0.56 (0.23–1.36)	0.79 (0.29–2.17)
RC/AL, traditional	26.1%	21.1%	0.57 (0.26–1.25)	0.85 (0.34–2.11)
RC/AL, new model	31.2%	29.5%	0.58 (0.22–1.54)	0.63 (0.21–1.91)
Facility bed size (OR is per 10 beds)	88.8 (56.5)	82.1 (51.2)	0.99 (0.93–1.06)	0.97 (0.90–1.04)
For-profit ownership	69.6%	72.6%	1.28 (0.64–2.55)	1.43 (0.69–2.90)
Assessment of BSRD				
Professional	59.9%	69.7%	1.79 (1.12–2.86)	1.82 (1.08–3.06)
Written or standardized	41.9%	53.5%	1.80 (1.07–3.03)	2.06 (1.16–3.66)
Perceived presence, current	39.0%	73.2%	4.11 (2.66–6.36)	3.45 (2.08–5.72)
Treatment of BSRD				
Professional	38.0%	69.3%	3.77 (2.26–6.29)	3.7 (2.05–6.66)
Informal	51.1%	73%	2.48 (1.59–3.86)	2.64 (1.62–4.3)
Residents receiving neuroleptics	27.1%	42.8%	2.11 (1.3–3.37)	2.19 (1.29–3.71)
Residents receiving antidepressant	39.1%	37.2%	0.86 (0.51–1.45)	0.83 (0.47–1.48)
Residents receiving hypnotics	15.8%	26.1%	1.67 (0.95–2.94)	1.91 (1.02–3.57)
Residents receiving ChEIs	28.6%	32.8%	1.23 (0.79–1.9)	1.55 (1.03–2.34)
Perceived success (at least quite a bit; if perceived agitated)	59.2%	73%	1.89 (1.22–2.92)	1.87 (1.10–3.16)

Table 2. (*Continued*)

Characteristic	Distribution of Characteristic as % or M (SD)		Relationship Between Characteristic and Presence of BSRD	
			Unadjusted	Adjusted[a]
	No BSRD	BSRD	OR (95% CI)	OR (95% CI)
Training to detect and treat BSRD[d]				
Supervisory staff (most in facility; ≥ 75%)	86.2%	65.3%	0.33 (0.17–0.64)	0.28 (0.15–0.53)
Direct care providers (most in facility; ≥ 75%)	81.2%	74.7%	0.77 (0.36–1.66)	0.63 (0.30–1.31)
Staff feels adequately trained to assess	91.3%	96.3%	2.77 (1.38–5.54)	2.63 (1.14–6.04)
Staff feels adequately trained to treat	93.5%	88.9%	0.55 (0.23–1.36)	0.43 (0.16–1.13)
Staff approach to dementia care	75 (6.3)	76.1 (6.8)	1.01 (0.96–1.06)	1.02 (0.97–1.07)
Staff work stress	1.8 (0.6)	1.8 (0.5)	0.90 (0.64–1.25)	0.83 (0.58–1.17)
Staff satisfaction	62 (10.6)	63.3 (10)	1.01 (0.98–1.01)	1.01 (0.99–1.01)
Facility physical environment characteristics				
SCUEQS	24.2 (5.1)	23.6 (4.9)	0.95 (0.89–1.01)	0.98 (0.91–1.06)
ALEQS	13.3 (4.3)	12.5 (3.6)	0.93 (0.87–0.99)	0.95 (0.90–1.01)

Notes: BSRD = behavioral symptoms related to dementia; RC/AL = residential care/assisted living; NH = nursing home; SCUEQS = Special Care Unit Environmental Quality Scale; ALEQS = Assisted Living Environmental Quality Scale. For the table, N = 328. Behavioral symptoms are assessed by supervisor report on the Cohen-Mansfield Agitation Inventory. Except as noted for training, all data are resident level, are of those residents for whom outcome data and supervisor data (required for adjustment) are available, and are from supervisor report. Due to missing data, n varies from 291 to 347, except in the case of perceived success of treatment, which is relevant only for those with agitation and for whom there are data for 294 (85%) of subjects.

[a]Adjusted for male gender, non-White race, age, cognitive status, number of number of 11 comorbidities (congestive heart failure; high blood pressure or hypertension; myocardial infarction, heart attack, angina, arrhythmias, or other heart problem; diabetes; kidney disease or renal insufficiency; arthritis, rheumatism, degenerative joint disease, lupus, erythematosis, or scleroderma; fractured bones or osteoporosis; cerebrovascular disease, stroke, TIA, or CVA; hemiplegia or paraplegia; asthma, emphysema, bronchitis, or COPD; schizophrenia, manic–depressive disorder, or mental retardation), and impairments in seven activities in daily living (bed mobility, transfer, locomotion, dressing, eating, toilet use, hygiene).

[b]Cognitive status is based on Mini-Mental State Examination (MMSE) or Minimum Data Set–Cognition Scale (MDS-COGS) scores if the MMSE is missing (n = 51), MMSE cutpoints for mild, moderate, severe, and very severe are ≥ 18, 11–17, 3–10, 0–2; respective MDS-COGS cutpoints are 0–1, 2–3, 5–8, 9–10. Depression: ≥ 7 points on the Cornell Scale for Depression in Dementia; pain: ≥ 2 points on the Philadelphia Geriatric Center Pain Intensity Scale; activity participation–low: < 9 (median) on the Albert Quality of Life Scale; mobility–moderate-high limitation: on feet during less than 25% of observation over 3 hours and/or demonstrating a position or location change at least once but less than 10% of consecutive observations (moderate impairment) or never being on feet and not changing position or location across any 2 consecutive observation periods (high impairment); food/fluid consumption–low: ate ≤ 8 ounces on the Structured Meal Observation. BSRD, depression, and pain are from supervisor report, activity is from care provider report, and immobility and consumption are based on direct observation.

[c]There was an effect modification for the type of long-term care facility (NH vs RC/AL facility) on the association between agitation and pain. Thus, we are reporting the OR separately for the facility type (p for interaction was .019).

[d]Data regarding supervisory staff training and direct care provider training (first two variables) are facility level and reported by administrators. Staff feelings of training adequacy are reported by the one supervisor (or direct care provider if supervisor data are missing) who is most involved in the resident's care; adequately is quite or extremely well trained.

ity, and function), these differences remained significant ($p < .05$). Detected differences in the care for BSRD between nursing homes and RC/AL need to be interpreted with caution, though, because facilities were not representative of all nursing home and RC/AL facilities, nor was the sample size adequate to detect small differences between facility types.

Not surprisingly, residents with BSRD were more likely to have had formal assessment and management of BSRD and to be perceived by staff to have more BSRD; that is, treatment was a likely response to their BSRD. However, despite recognition and treatment, current management methods are insufficient in responding to the need of dementia residents with BSRD. We found no association between BSRD and facility characteristics such as type, size, ownership, and physical environment. Although residents in facilities in which more supervisory staff were trained to detect and treat BSRD were less likely to display BSRD, we found no association between BSRD and direct care provider approaches to dementia care, work stress, and satisfaction. Further, individual staff members who felt adequately trained to assess BSRD were more likely to report BSRD in their residents, which may reflect their enhanced ability to recognize these symptoms. While power may have been insufficient to detect weak associations between BSRD and care provider (and environmental) factors, the impact of these factors is clearly minimal in the presence of cognitive deficit, depressed mood, and immobility.

One caveat to the findings reported herein is that they are limited by their cross-sectional nature. Also, they relied on caregiver ratings. However, while such measures are subjective, this type of rating may be more valid than observation because it captures rare but clinically relevant BSRD (Cohen-Mansfield, 1995).

In conclusion, long-term care facilities, including nursing homes and RC/AL, are working to meet the needs of residents with BSRD. Based on our findings of the association between BSRD and two modifiable factors (resident depression and staff training), developing a program that includes depression detection and management, as well as staff training in BSRD management, may be a valuable next step to improve the care of long-term care residents with BSRD.

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Characteristics Associated With Mobility Limitation in Long-Term Care Residents With Dementia

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This article describes the prevalence, assessment, and treatment of, as well as characteristics associated with, mobility limitation in 343 residents with dementia in 45 assisted living facilities and nursing homes. Overall, 89% of residents had some degree of mobility limitation. Mobility limitation was associated with fewer behavioral symptoms, low fluid intake, professional assessment, and professional and informal treatment.

Key Words: Mobility, Nursing home, Residential care, Assisted living

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Background

Maintenance of mobility is an important component of quality of life for all individuals, including those in long-term care facilities; in fact, long-term care residents and staff identify mobility as pivotal to residents' quality of life (Bourret, Bernick, Cott, & Kontos, 2002; Trudeau, Biddle, & Volicer, 2003). Further, mobility limitation leads to increased health care utilization, pressure sores, muscle atrophy, bone loss, pneumonia, incontinence, constipation, and general functional decline (Jirovec & Wells, 1990; Mahoney, Sager, & Jalaluddin, 1999; Trudeau et al.).

It is no surprise that the Minimum Data Set mandates quarterly assessments of mobility among nursing home residents. Care for mobility limitation needs to reflect resident characteristics (e.g., dementia, vision, cerebrovascular condition, age, and overall functional status) and the structure and process of care, such as the availability of handrails (structure) and staff training and assessment (process). Care provided by the facility staff is an important component of maintenance and/or restoration of mobility because staff members are the ones who typically identify and assist with mobility problems (Hyatt, 1997).

Based on Donabedian's (1988) structure, process, and outcome model, this article examines components of the care environment and how they relate to mobility for residents with dementia living in nursing homes and residential care/assisted living (RC/AL) settings. Until now, the study of mobility limitation in long-term care has been largely limited to nursing home care. Little information is known about the status and mobility-related care of residents in assisted living settings. Given the growth of this form of care, this study describes the mobility of older adults with

dementia in RC/AL and nursing homes and examines structural and process characteristics that relate to mobility limitation.

Methods

Data for these analyses were gathered on 237 residents in 35 residential care facilities and 106 residents in 10 nursing homes in four states, as part of the Dementia Care study of the Collaborative Studies of Long-Term Care (CS-LTC). All residents had a diagnosis of dementia. Data collection was conducted on-site between September 2001 and February 2003. For each resident, data collectors conducted interviews with: (a) the direct care provider who provided hands-on care and knew the most about the resident's care, health, mood, and daily activities; (b) the supervisor (i.e., staff member above a direct care provider level) who knew the most about the resident; (c) the facility administrator; and (d) a family member. Data collectors also gathered observational data on these 343 residents during the course of a single day. This study's analyses were restricted to those residents. Observations also were conducted on the physical environment of each facility. Further details about the Dementia Care study are in the introduction to this journal.

Measures

Dependent variable.—The Dementia Care study defined mobility based on observation of three characteristics: being on one's feet, changing position, and changing location. Resident-specific data on each of these characteristics were observed during 5-minute intervals between 10 and 11 a.m., 1 and 2 p.m., and 4 and 5 p.m. on one day in each study facility (for a maximum of 36 observations per resident). These times were chosen because they sample the most common activity periods (i.e., when sleep, meals, and morning personal care are least likely to occur). If a scheduled period of observation included a meal, the observation time was adjusted so as to exclude the meal. Up to three residents were observed at a time by each data collector.

Each characteristic was coded to reflect the resident's predominant activity during a 5-minute observation period. Position was noted as on feet, sitting, or lying down. On feet was coded when the resident was standing or walking with or without assistance. Location was coded as bedroom, indoor public area, outdoor public area, or off-site. A change in position was inferred if the resident was observed in two different positions in two sequential 5-minute observations; change in location was similarly defined.

Based on the three characteristics, residents were assigned to one of four levels of mobility limitation. First, if the resident was on his or her feet greater than or equal to 25% of the observations, the resident was coded as having "no mobility limitation." If the resident was on his or her feet less than 25% of obser-

vations and did not move (i.e., change position or location between consecutive observations), the resident was coded as having "high mobility limitation." If the resident was on his or her feet less than 25%, but moved between 10% or more of observations, he or she was coded as "low mobility limitation," while those who moved fewer than 10% of observations were coded as having a "moderate mobility limitation."

Independent variables, resident.—Cognition was assessed with the Mini-Mental State Examination (MMSE) and the Minimum Data Set Cognition Scale (MDS-COGS); functional status with the Minimum Data Set Activities of Daily Living Scale (MDS-ADL; minus the mobility items), and comorbidity through a list of 11 conditions. Further details about the independent variables can be found in the footnotes to Table 2. Behavioral symptoms were assessed with the Cohen-Mansfield Agitation Inventory; depression using the Cornell Scale for Depression in Dementia; pain with the Philadelphia Geriatric Center Pain Intensity Scale; and low food and fluid intake with the Structured Meal Observation. Family members rated their current involvement on a scale from 1 (very low) to 5 (very high). Supervisors rated resident's vision as adequate, impaired, highly impaired, or severely impaired.

Independent variables, facility.—Staff members, both direct care providers and supervisors, were asked how well trained they felt in identifying mobility limitation and in helping residents with their mobility limitation. Facility administrators estimated the proportion of staff who had received formal training in detecting and treating mobility limitation.

Supervisors answered several questions regarding assessment and treatment specific to the residents under study: whether the resident had been formally assessed for mobility limitation in the previous year using a written, standardized instrument and/or by a medical doctor or physical therapist; whether or not the resident had been treated for mobility limitation; whether or not the resident used any of a variety of assistive mobility devices (e.g., cane, wheelchair, walker); to what degree they felt treatment was successful; and to what extent limitation in mobility was present (perceived presence). Finally, the environment was assessed by observation and two scales were constructed: the Special Care Unit Environmental Quality Scale (SCUEQS) and the Assisted Living Environmental Quality Scale (ALEQS).

Analysis

We computed simple descriptive statistics—means and standard deviations for continuous measures and percentages for categorical measures—by setting (nursing home vs RC/AL). We completed statistical comparison of these characteristics by setting by fitting linear or logistic (for continuous and binary characteristics, respectively) models, using generalized estimat-

ing equations (GEE; Diggle, Heagerty, Liang, & Zeger, 2002), to control for subject clustering within facility through an exchangeable correlation structure; these models have setting as the single explanatory variable. Similarly, we computed descriptive statistics for those observed to have no or low mobility limitation and for those with a moderate to high mobility limitation. We used a four-level ordinal mobility measure as the dependent variable in partial proportional odds logistic regression to estimate odds ratios and 95% confidence intervals for greater mobility limitation. This procedure estimates separate odds ratios for the three cumulative logits for independent variables for which the proportional odds assumption was not met (Stokes, Davis, & Koch, 2000). We estimated adjusted odds ratios, controlling for age, gender, race, cognitive impairment (very severe, severe, moderate, vs mild), number of comorbid conditions, and number of nonmobility related ADL dependencies. We also tested interactions of predictors with setting. Both unadjusted and adjusted models accounted for resident clustering within facility using GEE.

Results

We coded a total of 11,842 observations, with 93% of residents having at least 30 (out of a maximum of 36) observations. The average age of the residents was 84.8 ($SD = 7.2$), 80% were female, and 90% were White. The average family involvement score was 3.8 ($SD = 1.2$), representing a high level of involvement.

Table 1 describes the mobility status of the sample, and compares RC/AL and nursing home residents by mobility limitation and selected facility components. There was no significant difference in the distribution of residents' mobility limitation across facility type. Overall, about 11% of residents had no mobility limitation, 39% had low limitation, 36% had moderate mobility limitation, and 14% had high mobility limitation.

However, there was a significant difference in assessment and professional treatment between the two types of facilities. Residents in nursing homes were more likely to receive professional (70% vs 41%, $p = .022$) and standardized (64% vs 35%, $p = .010$) assessments of mobility. Residents in nursing homes were also more likely to receive professional treatment (from a medical doctor or physical therapist) for mobility limitation (41% vs 19%, $p = .012$). Residential care facilities scored higher than nursing homes on the special care unit environmental measure ($M = 26$ vs 21, $p = .003$).

Table 2 shows the association between selected resident and facility characteristics and mobility limitation. Residents who had behavioral symptoms had lower odds of being in the high mobility impairment group than those without behavioral symptoms (adjusted OR = .40, 95% CI .17–.91). Residents with low fluid intake were more likely to have a higher level of mobility impairment than residents with adequate fluid intake (adjusted OR = 1.73, 95% CI 1.08–2.79). There was no significant association between other

Table 1. Prevalence of Mobility Limitation and Relevant Components of Care in Dementia Care Study Sample, by Setting

Mobility Limitation	RC/AL (N = 237) % or M (SD)	NH (N = 106) % or M (SD)	p^a
Prevalence[b]			
No mobility limitation	11.0	12.3	.880
Low mobility limitation	40.5	34.9	
Moderate mobility limitation	33.8	40.6	
High mobility limitation	14.7	12.2	
Assessment			
Professional	40.7	70.2	.022
Written or standardized	35.2	64.3	.010
Perceived presence, current	29.3	44.0	.090
Treatment			
Professional	19.4	40.5	.012
Informal	28.1	36.9	.205
Use of assistive mobility device	49.2	51.8	.716
Perceived success (if perceived mobility limitation)	60.0	57.1	.765
Training to detect and treat[c]			
Supervisory staff			
None in facility	12.2	0	.791
Some in facility	13.1	34.9	
Most in facility (> 75%)	74.7	65.1	
Direct care providers			
None in facility	15.3	0	.407
Some in facility	11.4	13.2	
Most in facility (> 75%)	73.4	86.8	
Staff feels adequately trained to assess	93.5	90.6	.536
Staff feels adequately trained to treat	87.9	89.6	.843
Environmental characteristics[c]			
SCUEQS	26.2 (5.6)	20.7 (2.8)	.003
ALEQS	13.9 (4.1)	11.1 (2.6)	.061

Notes: RC/AL = residential care/assisted living; NH = nursing home; SCUEQS = Special Care Unit Environmental Quality Scale; ALEQS = Assisted Living Environmental Quality Scale. Mobility was defined on the basis of three observed characteristics: being on one's feet, changing position, and changing location. Except as noted for "training," all data are resident-level and from those residents for whom outcome data (i.e., mobility) were available. Due to missing data, N varies from 182 to 237 (RC/AL) and 84 to 106 (NH), except in the case of "perceived success" of treatment, which was relevant only for those with mobility limitations and for whom there were data for 151 (44%) of subjects.

[a]Adjusted for facility-level clustering using generalized estimating equations (exchangeable correlation matrix); p values are based on score statistics.

[b]See text for explanation of cutpoints.

[c]Data regarding supervisory staff training and direct care provider training (first two items) are facility level and reported by administrators. Staff feelings of training adequacy were reported by the one supervisor (or direct care provider, if supervisor data are missing) who was most involved in the resident's care; "adequately" is quite or extremely well trained.

resident characteristics measured in this study and mobility limitation.

In terms of structural facility characteristics, residents of RC/AL facilities with fewer than 16 beds had higher levels of mobility limitation than nursing home residents (adjusted OR = 2.23, 95% CI 1.03–4.82),

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Characteristic	Distribution of Characteristic as % or M (SD)		Relationship Between Characteristic and Higher Levels of Mobility Limitation	
	No or Low Mobility Limitation (n = 147)	Moderate to High Mobility Limitation (n = 135)	Unadjusted OR (95% CI)[b]	Adjusted[a] OR (95% CI)[b]
Resident[c]				
Severe to very severe cognitive deficit	57.5	65.2		
High, moderate, or low limitation (vs none)			0.50 (0.22, 1.11)	0.40 (0.16, 1.00)
High to moderate limitation (vs none or low)			1.40 (0.87, 2.27)	1.16 (0.68, 1.99)
High limitation (vs none, low, or moderate)			1.26 (0.60, 2.65)	1.05 (0.49, 2.24)
Depressed	23.9	21.3	0.85 (0.56, 1.30)	0.93 (0.59, 1.46)
Behavioral symptoms	57.7	60.6		
High, moderate, or low limitation (vs none)			0.40 (0.17, 0.92)	0.47 (0.21, 1.07)
High to moderate limitation (vs none or low)			1.13 (0.69, 1.84)	0.99 (0.57, 1.70)
High limitation (vs none, low, or moderate)			0.46 (0.22, 0.97)	0.40 (0.17, 0.91)
Low activity	41.7	53.1	1.39 (0.91, 2.12)	1.30 (0.80, 2.10)
High pain	17.0	25.4	1.75 (0.99, 3.07)	1.42 (0.83, 2.44)
Low food intake	51.0	57.1	1.42 (0.98, 2.04)	1.36 (0.93, 1.98)
Low fluid intake	42.9	62.3	1.79 (1.13, 2.83)	1.73 (1.08, 2.79)
Impaired vision	39.7	44.4	1.09 (0.70, 1.70)	0.85 (0.49, 1.47)
Family involvement	3.6 (1.3)	3.6 (1.3)	1.09 (0.90, 1.33)	1.04 (0.85, 1.28)
Facility				
Facility type				
NH	27.9	33.3	1.0	1.0
RC/AL, < 16 beds	15.6	17.0	2.16 (0.93, 5.06)	2.23 (1.03, 4.82)
RC/AL, Traditional	20.4	20.7	1.07 (0.54, 2.14)	1.54 (0.80, 2.94)
RC/AL, New-model	36.1	28.9	0.95 (0.42, 2.11)	1.15 (0.51, 2.60)
Facility size (OR per 10 beds)	76.4 (50.3)	83.6 (55.3)	0.98 (0.93, 1.04)	0.98 (0.93, 1.03)
For-profit ownership	75.7	60.7		
High, moderate, or low limitation (vs none)			0.33 (0.12, 0.88)	0.28 (0.10, 0.82)
High to moderate limitation (vs none or low)			0.48 (0.29, 0.81)	0.57 (0.33, 1.00)
High limitation (vs none, low, or moderate)			1.62 (0.70, 3.72)	1.95 (0.86, 4.43)
Assessment of mobility limitation				
Professional	39.7	62.1	2.28 (1.59, 3.28)	2.20 (1.47, 3.30)
Written or standardized	39.7	50.8	1.45 (0.98, 2.14)	1.43 (0.92, 2.20)
Perceived presence, current	16.9	48.8	4.74 (2.64, 8.52)	4.67 (2.43, 9.00)
Treatment of mobility limitation				
Professional	15.6	37.1	2.58 (1.60, 4.16)	2.11 (1.24, 3.61)
Informal	20.9	41.6	2.37 (1.49, 3.75)	1.82 (1.03, 3.22)
Use of assistive mobility device	43.0	57.1		
High, moderate, or low limitation (vs none)			5.54 (2.21, 13.88)	3.34 (1.28, 8.74)
High to moderate limitation (vs none or low)			1.77 (1.09, 2.87)	1.23 (0.69, 2.20)
High limitation (vs none, low, or moderate)			1.25 (0.60, 2.60)	0.96 (0.43, 2.13)
Perceived success (if perceived mobility limitation)	68.5	53.6	0.51 (0.24, 1.08)	0.51 (0.24, 1.10)
Training to detect and treat mobility limitation[d]				
Supervisory staff				
None in facility	12.2	8.1	1.0	1.0
Some in facility	21.1	20.0	0.58 (0.19, 1.78)	0.55 (0.17, 1.73)
Most in facility (> 75%)	66.7	71.9	0.84 (0.28, 2,50)	0.93 (0.32, 2.68)
Direct care providers				
None in facility	15.0	10.4	1.0	1.0
Some in facility	8.2	14.1	0.92 (0.28, 2.96)	0.65 (0.20, 2.17)
Most in facility (> 75%)	76.9	75.6	0.68 (0.28, 1.68)	0.63 (0.24, 1.65)
Staff feels adequately trained to assess	91.8	92.6	1.26 (0.60, 2.65)	1.08 (0.47, 2.50)
Staff feels adequately trained to treat	87.0	86.7	0.87 (0.48, 1.57)	0.90 (0.49, 1.65)

(Table continues on next page)

while those in for-profit facilities have lower odds of having any mobility limitation compared to residents in not-for-profit facilities (adjusted OR = 0.28, 95% CI 0.10–0.82). Process facility characteristics such as professional assessment (adjusted OR = 2.20, 95% CI 1.47–3.30) and perceived presence of mobility limitation (adjusted OR = 4.67, 95% CI 2.43–9.00) were associated with higher levels of mobility limitation.

Table 2. (*Continued*)

Characteristic	Distribution of Characteristic as % or M (SD)		Relationship Between Characteristic and Higher Levels of Mobility Limitation	
	No or Low Mobility Limitation (*n* = 147)	Moderate to High Mobility Limitation (*n* = 135)	Unadjusted OR (95% CI)[b]	Adjusted[a] OR (95% CI)[b]
Environmental Characteristics				
SCUEQS	24.2 (5.1)	24.1 (5.7)		
High, moderate, or low limitation (vs none)			1.11 (1.03,1.19)	1.11 (1.02, 1.20)
High to moderate limitation (vs none)			1.00 (0.96, 1.04)	1.02 (0.97, 1.07)
High limitation (vs none, low, or moderate)			0.99 (0.92, 1.07)	1.02(0.94, 1.11)
ALEQS	12.8 (4.0)	12.6 (4.0)		
High, moderate, or low limitation (vs none)			1.14 (1.04,1.25)	1.18 (1.06, 1.31)
High to moderate limitation (vs none)			0.98 (0.93, 1.04)	1.03 (0.96, 1.10)
High limitation (vs none, low, or moderate)			0.94 (0.84, 1.05)	0.99(0.88, 1.12)

Notes: NH = nursing home; RC/AL = residential care/assisted living; SCUEQS = Special Care Unit Environmental Quality Scale; ALEQS = Assisted Living environmental Quality Scale. Mobility limitation was defined on the basis of three characteristics: being on one's feet, changing position, and changing location. See text for explanation of cutpoints. Except as noted for "training," all data are resident level, and from those residents for whom outcome data (i.e., mobility) and supervisor data (required for adjustment) were available and from supervisor report. Due to missing data, N varies from 264 to 282, except in the case of "perceived success" of treatment, which was relevant only for those with mobility limitations and for whom there were data for 138 (48.9%) of subjects.

[a]Adjusted for male gender, non-White race, age, cognitive status, number of eleven comorbidities (congestive heart failure; high blood pressure or hypertension; myocardial infarction, heart attack, angina, arrhythmias, or other heart problem; diabetes; kidney disease or renal insufficiency; arthritis, rheumatism, degenerative joint disease, lupus, erythematosis, or scleroderma; fractured bones or osteoporosis; cerebrovascular disease, stroke, TIA, or CVA; hemiplegia or paraplegia; asthma, emphysema, bronchitis or COPD; schizophrenia, manic-depressive disorder, or mental retardation) and impairments in four activities of daily living (dressing, eating, toilet use, hygiene).

[b]Based on a partial proportional odds logistic regression model for the four-level ordinal mobility limitation measure. The OR is interpreted as the relative odds of having greater versus lesser mobility limitation compared to the reference group (or per unit for continuous characteristics). CIs are based on robust variance estimation using generalized estimating equations with an exchangeable working correlation to control for within-in-facility clustering.

[c]Cognitive status is based on Mini-Mental State Examination (MMSE) or Minimum Data Set–Cognition (MDS-COGS) scores, if the MMSE is missing (N = 17). MMSE cutpoints for mild, moderate, severe, and very severe are: $\geq$ 17, 10–16, 3–9, 0–2; respective MDS-COGS cutpoints are: 0–1, 2–4, 5–6, 7–10. Depressed: $\geq$ 7 on the Cornell Scale for Depression in Dementia; behavioral symptoms: any behaviors at least weekly on the Cohen-Mansfield Agitation Inventory; low activity: < 9 (median) on the Albert Patient Activity Scale; pain: $\geq$ 2 points on the Philadelphia Geriatric Center Pain Intensity Scale; low food and fluid intake: consumed $\leq$ ¾ of meal and drank $\leq$ 8 oz on Structured Meal Observation. Depression, behavioral symptoms, and pain were taken from supervisor report, activity was taken from care provider report, and intake was based on direct observation.

[d]Data regarding supervisory staff training and direct care provider training (first two variables) are facility-level and reported by administrators. Staff feelings of training adequacy were reported by the one supervisor (or direct care provider, if supervisor data are missing) who was most involved in the resident's care; "adequately" is quite or extremely well trained.

Similarly, the process facility characteristic of treatment, both professional (adjusted OR = 2.11, 95% CI 1.24–3.61) and informal (adjusted OR = 1.82, 95% CI 1.03–3.22), was associated with higher levels of mobility limitation than that found in residents who did not receive treatment for mobility limitation. Residents using an assistive mobility device also had greater odds of having some mobility impairment (adjusted OR = 3.34, 95% CI 1.28–8.74) than those not using such devices. Finally, the structural variable of a higher environmental quality score was associated with having some degree (high, moderate, or low) of mobility limitation versus having no mobility limitation.

Discussion

Direct observation of 343 residents with dementia in RC/AL facilities and nursing homes revealed that 89% of the residents had some level of mobility limitation, as defined in this study. Residents with high mobility limitation (14%) did not change position or location during 3 hours of observation. Those with moderate limitation (36%) were on their feet fewer than 25% of observations, but changed position and or location at least once but fewer than 10% of observations. An additional 39% of the residents had low mobility limitation (on feet fewer than 25% of observations, but changed location 10% or more of observations), and the other 11% percent had no mobility limitation (i.e., were on their feet 25% or more of observations). Proportions were similar in RC/AL facilities and nursing homes.

These numbers are similar to other findings that document high levels of mobility limitation (75–85%) in long-term care facilities (Horn et al., 2002; Pope & Tarlov, 1991). Despite the fact that nursing homes typically have residents with higher levels of functional limitations than RC/AL facilities (Zimmerman et al., 2003), there was no significant difference in mobility limitation across the two settings among residents with dementia in this study. However, a more detailed analysis of the type of facility found higher levels of mobility limitation in RC/AL facilities with fewer than 16 beds compared to nursing homes. It may be that

smaller facilities offer less opportunity for mobility, and/or that there is less access to mobility assistive devices in these less resource-intense settings. Also, facilities with higher environmental scores (e.g., better lighting contrast, handrails) may enable or facilitate management of residents with higher levels of mobility limitation.

Residents who exhibit behavioral symptoms were less likely to have high mobility limitation than those who did not; the association of behavioral symptoms with wandering may account for this relationship. Residents who used assistive mobility devices were more likely to have higher mobility limitation, and this relationship has been noted in other studies (Verbrugge & Sevak, 2002). Low fluid intake (observed during one meal) also remained positively associated with mobility limitation after adjustment for age, gender, race, cognitive impairment, ADLs, and comorbidities. Thus, there is a group of residents who maybe at risk for both mobility-related morbidity (e.g., pressure ulcers) and dehydration. Analysis of this group indicates that only 45% of these residents are very severely cognitively impaired (and may be end-stage dementia); hence, efforts may be indicated to focus care on this vulnerable population.

In terms of process variables, higher levels of assessment and treatment also were associated with having a higher level of mobility limitation. Since assessment and treatment were obtained from supervisor report and mobility was obtained by observation, it is unlikely that the association between assessment and treatment and mobility is due to measurement bias. More likely, this finding reflects that RC/AL and nursing home staff are attentive to residents and intervene when mobility problems occur. However, 38% to 63% of those with moderate to high limitation were not professionally assessed or treated, perhaps indicating the need for more attention for some of these more impaired residents.

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Characteristics Associated With Pain in Long-Term Care Residents With Dementia

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This article describes the prevalence, assessment, and treatment of pain, as well as characteristics associated with pain, in 331 residents with dementia in 45 assisted living facilities and nursing homes. Overall, 21% of residents had pain, and pain was more commonly reported in for-profit facilities, and for those receiving professional assessment and treatment.

Key Words: Discomfort, Cognitive impairment, Nursing homes, Assisted living, Residential care

Pain is common in residents of long-term care facilities, with prevalence estimates in nursing homes ranging from 49% to 83% (Fox, Raina, & Jadad, 1999). Pain leads to negative consequences, including impaired mobility, depression, and social withdrawal (Ferrell, 1991; Ferrell, Ferrell, & Osterweil, 1990; Parmelee, Katz, & Lawton, 1991); for those with dementia, pain may exacerbate cognitive decline and agitated behavior (Buffum, Miaskowski, Sands, & Brod, 2001; Feldt, Warne, & Ryden, 1998). Pain is likely no less common in those with dementia than in the cognitively intact (Farrell, Katz, & Helme, 1996), although it is less frequently reported (Cohen-Mansfield & Lipson, 2002; Parmelee, Smith, & Katz, 1993; Sengstaken & King, 1993) and treated (Horgas & Tsai, 1998; Morrison & Siu, 2000). Reputed causes of underdetection include inability of residents with dementia to communicate their discomfort verbally (Weissman & Matson, 1999); lack of staff training (Ferrell, 1995; Weissman & Matson) and formal assessment (Weiner, 2002); and staff attitudinal barriers (Mrozek & Werner, 2001; Weiner & Rudy, 2002). Though challenging, particularly in noncommunicative demented residents, standardized assessment is recommended (Ferrell, 1995; Weiner). Once pain is identified, treatment should be administered, using both pharmacologic and nonpharmacologic approaches (AGS Panel on Persistent Pain in Older Persons, 2002; Ferrell, 1995).

While the process of pain care for cognitively impaired nursing home residents has received some research attention, less work has focused on pain in demented individuals in residential care/assisted living (RC/AL). Furthermore, existing research provides little understanding of factors that are associated with staff reporting of resident pain in both types of long-term-care settings. Therefore, this study has two objectives: (a) describe the prevalence and relevant components of pain management in nursing homes and RC/AL; and (b) identify resident and facility characteristics associated with staff reports of pain in individuals with dementia.

Methods

Sample

As part of the Dementia Care project of the Collaborative Studies of Long-Term Care, (Zimmerman et

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al., 2005, this issue), residents aged 65 and older with diagnosed dementia were randomly selected from each of 10 nursing homes and 35 RC/AL facilities in four states. The participation rate was 73% among eligible residents; a total of 421 residents were enrolled. These analyses are based on the 331 residents for whom the care supervisor provided pain data. The care supervisors in this study were predominantly nurses (77% were registered nurses [RNs] or licensed practical nurses [LPNs]), and most (75%) had been in their current position for at least one year.

Measures

Pain was measured using the Philadelphia Geriatric Center–Pain Intensity Scale (PGC–PIS; Parmelee et al., 1991), and the 0–10 pain numeric rating scale (NRS; Jensen & Karoly, 1992). For these analyses, residents scoring 2 or more on the PGC–PIS (range $1 =$ no pain to $5 =$ extreme pain) are considered to have pain. This threshold corresponds to an average across the six items of "a little" pain or worse; all residents meeting this definition had a response of "moderate" pain or worse on at least one item. Both instruments were administered to the supervisor overseeing each resident's care (for all participants) and to those residents who scored 10 or greater on the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975). The PGC–PIS had excellent internal consistency reliability for both supervisor and resident samples (Cronbach's $\alpha = 0.89$, 0.88, respectively). Both also correlated well with the NRS (Spearman $r = 0.69$, supervisor; $r = 0.68$, resident).

In accordance with the conceptual framework of structure, process, and outcome (Donabedian, 1980) as operationalized for this study, supervisors were administered a series of questions regarding pain assessment, treatment, and training. They reported perceived presence of pain in the past week ("a moderate amount" or more) and formal pain assessment in the past year (written, standardized assessment and/or by physician or nurse). Treatment included ongoing professional treatment, other treatment (including informal), and treatment success among residents with pain in the past year (with "quite" or "extremely" well constituting "perceived success"). Staff also reported perceived training adequacy (with "quite" or "extremely" well trained in identifying and helping with resident physical pain and discomfort classified as feeling adequately trained). Facility administrators reported on facility demographic characteristics and estimated the proportion of supervisory and direct care staff who received formal training in detecting and treating pain.

Resident cognition was assessed using the MMSE and the Minimum Data Set Cognition Scale (MDS-COGS; Hartmaier, Sloane, Guess, & Koch, 1994). Functional status was measured with the MDS-ADL (Morris, Fries, & Morris, 1999), and comorbidity as the number of 10 supervisor-reported conditions (detailed in Table 1). Residents were classified as having arthritis based on supervisor report of resident arthritis, rheumatism, degenerative joint disease, lupus erythematosis, or scleroderma.

Current medication use was ascertained by asking the supervisor to list all prescription and nonprescription medications used four or more days in the prior week. Residents taking one or more analgesics, antipyretics, nonsteroidal anti-inflammatory drugs (NSAIDs), and/or narcotics were identified as receiving pain medication. Aspirin was excluded because most aspirin use in long-term care is for cardiovascular disease prevention and is at a dosage that is subtherapeutic for pain.

Analysis

Descriptive statistics were computed separately for RC/AL facilities and nursing homes, with statistical comparison of settings for these characteristics computed using Generalized Estimating Equations (GEE; Diggle, Heagerty, Liang, & Zeger, 2002), applied to linear or logistic (for continuous and binary characteristics, respectively) models and adjusting for participant clustering by facility. Descriptive statistics were similarly computed for those for whom the supervisor reported pain and those without pain. Odds ratios and 95% confidence intervals were estimated using separate logistic regression models for each characteristic, controlling for clustering using GEE empirical standard error estimates and exchangeable correlation. Adjusted odds ratios were estimated controlling for resident age, gender, non-White race, cognitive impairment, comorbid conditions, and activities of daily living (ADL) dependencies. To ensure that factors associated with pain did not differ between nursing homes and assisted living facilities, a setting-by-characteristic interaction term was tested in each multivariable logistic model.

Results

Among the 331 residents for whom the supervisor reported on pain, the average age was 84.4 years, 82% were female, and 11% non-White. Ninety-two (27.8%) residents were sufficiently cognitively intact (MMSE $\geq$ 10) to report their own pain.

Table 1 describes the pain status of the sample. None of the measures of pain prevalence differ significantly between nursing home and RC/AL residents. Based on supervisor report, 20% to 23% had pain; among residents who self-reported, the prevalence was higher (25% to 39%). For residents with both supervisor and self-report, there was 62% agreement ($\kappa = 0.10$) for the presence of pain (PGC–PIS $\geq$ 2).

More than one third of residents (34.7%) had no formal pain assessment. Formal assessment, all types of pain treatment, and staff training in assessment and treatment were all reported more often by nursing homes than RC/AL facilities. More than three fourths of supervisors in both settings reported success in treating resident pain and more than 90% reported

feeling adequately trained to identify and help with resident pain.

When associations between resident characteristics and pain were evaluated (Table 2), depression and arthritis were identified as significant, independent correlates of pain. No association was noted between resident cognitive status and supervisor pain report.

When facility factors were related to pain status, residents in for-profit facilities were found to be more likely to have supervisors reporting resident pain, an effect undiminished by covariate adjustment. To explore this finding, we examined whether other aspects of pain care differed between profit and nonprofit facilities. In these post hoc analyses, we found that residents in for-profit facilities were less likely to undergo professional pain assessment (54% vs 81%, $p = .008$). Also, fewer residents in for-profit homes were receiving pain medication, both overall (34% vs 61%, $p = .015$) and among those with pain (53% vs 91%, $p = .041$). Consequently, when the association between for-profit status and pain was adjusted for professional assessment and medication use, along with the other covariates, the relationship strengthened (AOR = 4.3, 95% CI 1.8–10.1).

Other statistically significant associations noted between facility factors and reported pain included professional assessment and all forms of pain treatment. Still, one quarter of those with pain had not been professionally assessed, 60% had not received a standardized assessment, and 19% of residents with pain were receiving neither pain medication nor ongoing professional treatment. Treatment was less likely to be perceived as successful in those in whom current pain was reported (AOR = 0.4, 95% CI 0.2–0.8). No interactions between resident or facility characteristics and setting (nursing home vs RC/AL facility) were statistically significant (all $p > .05$).

Discussion

We found few differences in pain prevalence and components of pain management between nursing homes and RC/AL facilities, the notable exception being that more nursing home residents received pain treatment, especially medications. Roughly 40% of residents with pain in both settings were receiving no pain medication and nearly one third (31.3%) were receiving no treatment for pain. Given the Joint Commission on Accreditation of Healthcare Organizations' mandate for regular pain assessment in nursing homes (Phillips, 2000), it is notable that a substantial minority of residents received no formal pain assessment and that assessment was only slightly more common in nursing homes than RC/AL facilities.

The prevalence of pain reported here, whether by resident or supervisor report (20% to 39%) appears lower than the frequently cited prevalence of up to 80% in previous nursing home studies. However, this disparity is due at least in part to our use of a threshold of 2.0 to denote pain, rather than a broader definition of "any" pain. Applying the latter criterion to our

Table 1. Prevalence of Pain and Relevant Components of Care in Dementia Care Study Sample, by Setting

Pain	M (SD) or %		
	RC/AL (n = 222)	NH (n = 109)	p^a
Prevalence			
Supervisor report			
Residents with pain (PGC–PIS ≥ 2)[b]	20.3	22.9	0.741
PGC–PIS	1.5 (0.6)	1.6 (0.6)	0.439
Pain Numeric Rating Scale (0–10)	1.1 (1.8)	0.9 (1.5)	0.718
Resident report[c]			
Residents with pain (PGC–PIS ≥ 2)[b]	38.9	25.0	0.318
PGC–PIS	1.9 (0.9)	1.6 (0.6)	0.228
Pain Numeric Rating Scale (0–10)	2.5 (3.0)	2.3 (2.6)	0.776
Assessment			
Professional	57.7	73.8	0.373
Written or standardized	28.6	55.1	0.076
Perceived presence, current	9.5	8.3	0.732
Treatment			
Professional	31.4	43.0	0.092
Informal	39.1	51.9	0.068
Current nonaspirin pain medication	34.4	58.9	0.008
Perceived success (if perceived pain; quite a bit or extremely)	78.5	78.9	0.764
Training to detect and treat[d]			
Supervisory staff			
None in facility	21.2	0.0	—
Some in facility	23.1	32.1	—
Most in facility (≥ 75%)	55.8	67.9	0.443
Direct care providers			
None in facility	43.3	11.0	—
Some in facility	19.7	19.3	0.266
Most in facility (≥ 75%)	37.0	69.7	0.042
Staff feels adequately trained to assess	94.6	94.5	0.853
Staff feels adequately trained to treat	92.8	93.6	0.717

Notes: RC/AL = residential care/assisted living; NH = nursing home; PGC–PIS = Philadelphia Geriatric Center–Pain Intensity Scale. Except as noted for training, all data are resident level, are of those for whom outcome data (i.e., pain) were available, and, except for the Resident report of prevalence of pain, are from supervisor report. Due to missing data, n of supervisor data varied from 209 to 222 (RC/AL) and 107 to 109 (NH), except "perceived success of treatment," which was relevant only for those perceived to have had pain in the past year and for whom there were data—121 (55%) and 76 (70%) RC/AL and NH participants, respectively.

[a]Adjusted for facility-level clustering using generalized estimating equations (GEE; exchangeable correlation matrix); p values are based on score statistics.

[b]Pain as per supervisor or resident report using the PGC–PIS.

[c]Data from resident interview (n = 72 RC/AL, 20 NH).

[d]Data regarding supervisory staff training and direct care provider training (first two items) are facility level and reported by administrators. Staff feelings of training adequacy were reported by the one supervisor (or direct care provider, if supervisor data are unavailable) who was most involved in the resident's care; "adequately" is quite or extremely well trained.

sample, the prevalence is 62% and 76% for supervisor and resident report, respectively. Further, our supervisor and resident mean PGC–PIS scores (1.53 and 1.80,

Table 2. Characteristics Associated With Substantial Pain, Unadjusted and Adjusted

Characteristics	Distribution of Characteristic as % or M (SD)		Relationship Between Characteristics and Presence of Pain	
	No Pain (PGC–PIS < 2)	Pain (PGC–PIS ≥ 2)	Unadjusted OR (95% CI)	Adjusted[a] OR (95% CI)
Resident[b]				
Cognitive status				
Mildly impaired	12.0	16.4	1.00	1.00
Moderately impaired	27.5	22.4	0.66 (0.27, 1.65)	0.50 (0.18, 1.38)
Severely impaired	23.3	28.4	1.03 (0.36, 2.89)	0.86 (0.27, 2.72)
Very severely impaired	37.2	32.8	0.76 (0.30, 1.96)	0.50 (0.15, 1.70)
Depressed	18.6	41.8	2.32 (1.13, 4.77)	2.91 (1.18, 7.21)
Behavioral symptoms	57.0	62.7	1.06 (0.49, 2.29)	1.16 (0.57, 2.36)
Low activity	49.8	33.8	0.65 (0.38, 1.11)	0.64 (0.37, 1.10)
Immobile	12.3	12.5	1.06 (0.49, 2.29)	0.79 (0.37, 1.69)
Low food intake	52.9	53.0	1.18 (0.64, 2.17)	1.03 (0.56, 1.87)
Low fluid intake	49.6	53.2	1.20 (0.67, 2.15)	1.14 (0.66, 1.99)
Arthritis	29.8	47.8	2.36 (1.45, 3.87)	2.02 (1.19, 3.42)
Facility				
Facility type				
Nursing home	31.8	37.3	1.00	1.00
RC/AL, < 16 beds	12.0	20.9	1.37 (0.44, 4.23)	1.45 (0.46, 4.59)
RC/AL, Traditional	24.8	17.9	0.50 (0.18, 1.44)	0.67 (0.22, 2.08)
RC/AL, New-model	31.4	23.9	0.54 (0.12, 2.31)	0.60 (0.15, 2.46)
Facility size (OR per 10 beds)	87.6 (53.4)	87.7 (52.0)	0.99 (0.91, 1.08)	0.99 (0.91, 1.07)
For-profit ownership	66.5	83.6	2.83 (1.34, 6.01)	2.99 (1.40, 6.39)
Assessment of pain				
Professional	59.9	75.0	2.61 (1.42, 4.79)	2.56 (1.37, 4.78)
Written or standardized	36.9	39.1	1.06 (0.59, 1.90)	1.01 (0.55, 1.84)
Perceived presence, current	1.6	37.3	23.31 (9.45, 57.5)	26.63 (8.82, 80.4)
Treatment of pain				
Professional	25.9	68.7	5.65 (3.62, 8.82)	5.43 (3.32, 8.87)
Informal	34.4	73.1	5.17 (2.87, 9.34)	5.39 (2.97, 9.80)
Current nonaspirin pain medication	37.9	59.7	2.85 (1.63, 5.00)	2.89 (1.53, 5.47)
Perceived success (if perceived in pain)	85.4	64.5	0.39 (0.18, 0.84)	0.39 (0.18, 0.84)
Training to detect and treat pain[c]				
Supervisory staff				
None in facility	9.4	27.3	1.00	1.00
Some in facility	29.4	16.7	0.24 (0.06, 1.00)	0.22 (0.05, 1.03)
Most in facility (≥ 75%)	61.2	56.1	0.41 (0.13, 1.31)	0.41 (0.13, 1.30)
Direct care providers				
None in facility	28.6	45.5	1.00	1.00
Some in facility	23.3	6.1	0.20 (0.06, 0.64)	0.20 (0.06, 0.67)
Most in facility (≥ 75%)	48.2	48.5	0.65 (0.26, 1.63)	0.58 (0.25, 1.35)
Staff feels adequately trained to assess	93.8	97.0	1.61 (0.75, 3.46)	1.42 (0.59, 3.45)
Staff feels adequately trained to treat	94.6	88.1	0.41 (0.16, 1.07)	0.48 (0.16, 1.41)

Notes: PGC–PIS = Philadelphia Geriatric Center–Pain Intensity Scale. For the table, $N = 325$; pain: $n = 67$; no pain: $n = 258$. Pain was assessed by supervisor report using the PGC–PIS, and "pain" refers to a score of 2 or more. Except as noted for training, all data are resident level, are of those for whom outcome data (i.e., pain) were available, and were from supervisor report. Due to missing data, n varied from 310 to 325, except in the case of "perceived success of treatment", which was relevant only for those perceived to have had pain in the past year and for whom there were data—192 (59%) participants.

[a]Adjusted for male gender, non-White race, age, cognitive status, number of 10 comorbidities (congestive heart failure; high blood pressure; myocardial infarction, angina, arrhythmias, or other heart problems; diabetes; kidney disease or renal insufficiency; fractured bones or osteoporosis; cerebrovascular disease, stroke, TIA, or CVA; hemiplegia or paraplegia; asthma, emphysema, bronchitis, or COPD; schizophrenia, manic-depressive disorder, or mental retardation), and impairments in seven activities of daily living (bed mobility, transfer, locomotion, dressing, eating, toilet use, hygiene).

[b]Cognitive status is based on Mini-Mental State Examination (MMSE) or Minimum Data Set–Cognition (MDS-COGS) scores, if the MMSE is missing ($n = 51$). Cutpoints for mild, moderate, severe, and very severe (MMSE) are ≥ 17, 10–16, 3–9, 0–2; MDS-COGS cutpoints are 0–1, 2–4, 5–6, 7–10. Depressed: ≥ 7 on the Cornell Scale for Depression in Dementia; low activity: < 9 on the Albert Patient Activity Scale; behavioral symptoms: any behaviors at least weekly on the Cohen-Mansfield Agitation Inventory; immobile: no position or location changes observed during 3 hours of observation; low food intake and low fluid intake: consumed ≤ ¾ of meal and drank ≤ 8 oz. on Structured Meal Observation. Arthritis: arthritis, rheumatism, degenerative joint disease, lupus erythematosis, or scleroderma. Depression, behavioral symptoms, and arthritis were from supervisor report; activity was from care provider report; and immobility and consumption were based on direct observation.

[c]Data regarding supervisory staff training and direct care provider training (first two items) were facility level and reported by administrators. Staff feelings of training adequacy were reported by the one supervisor (or direct care provider, if supervisor data are unavailable) who was most involved in the resident's care; "adequately" is quite or extremely well trained.

respectively) are remarkably similar to those for markedly impaired (1.47) and cognitively intact (1.80) groups previously reported (Parmelee et al., 1993). Finally, analgesic use—commonly used as an indirect measure of pain—was similar in our study (34% to 59%) to the prevalence reported in a recent review (Fox et al., 1999).

We found pain more common in for-profit facilities, independent of resident demographics and health status. This could be because more residents in for-profit facilities have pain or simply because their pain is more frequently recognized. The fact that both professional assessment and pain medication use are less common in for-profit facilities makes the latter explanation less plausible, however, and suggests a need for more assessment and care in these facilities.

We used proxy report as the primary pain measure. For the 27% of residents who administered a self-reported pain measure, agreement with the supervisor was modest, albeit similar to (Werner, Cohen-Mansfield, Watson, & Pasis, 1998) or better than (Horgas & Dunn, 2001; Weiner, Peterson, Ladd, McConnell, & Keefe, 1999) that reported by others. While a potential study limitation, proxy report allowed the standardized assessment of pain using a reliable, valid pain instrument (Parmelee, 1994; Parmelee et al., 1991; Parmelee et al., 1993) for the entire sample of cognitively impaired long-term-care residents (mean MMSE = 8.1). In fact, a recent study found that correlation between caregiver and care-recipient pain report was stronger for the PGC–PIS than for other pain measures examined (Krulewitch et al., 2000). The great majority (84%) of supervisors had known the residents for whom they reported pain for at least a year, and 88% reported that they knew the residents "pretty well" or "very well." Further, proxy report is salient because recognition of pain by staff is an essential first step in its effective management (Kamel, Phlavan, Malekgoudarzi, Gogel, & Morley, 2001), and we wished to identify correlates of this important endpoint. While it is not surprising that pain was noted in those for whom current treatment is reported, the finding that treatment is less likely to be deemed successful in those with pain suggests that staff are cognizant of the residents for whom pain management remains incomplete. This finding may be considered in conjunction with the very high proportion of staff who report feeling adequately trained to assess and treat pain in the residents under their care, perhaps implying that some staff are unaware of other techniques to treat pain or feel that additional intervention is either not warranted or unavailable.

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Characteristics Associated With Low Food and Fluid Intake in Long-Term Care Residents With Dementia

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This article describes the prevalence, assessment, and treatment of, as well as characteristics associated with, the food and fluid intake of 407 residents with dementia in 45 assisted living facilities and nursing homes. Overall, 54% of observed residents had low food intake, and 51% had low fluid intake. Staff monitoring of residents, having meals in a public dining area, and the presence of noninstitutional features were each associated with higher food and fluid intake.

Key Words: Cognitive impairment, Nursing homes, Assisted living, Malnutrition, Dehydration

Declining capacity to eat and drink independently, and subsequent malnutrition and dehydration, have long been recognized as serious problems for institutionalized elderly, particularly for those with impaired mobility and cognition (Van Ort & Phillips, 1995). Malnutrition, or undernourishment resulting from insufficient food intake, is reported in up to 85% of nursing home residents (Simmons & Reuben, 2000), and dehydration has been documented in as many as 60% of residents (Fries et al., 1997; Holben, Hassell, Williams, & Helle, 1999). Consequences of malnutrition include weight loss, infection, impaired wound healing, immune deficiency, development of pressure sores, and even mortality (Volicer, Warden, & Morris, 1999). Dehydration can result in constipation, urinary tract infections, renal disease, pneumonia, hypotension, and delirium (Spangler & Chidester, 1998; Volicer et al.).

The observed proportion of food and fluid consumed (of that served) is commonly used to identify problematic eating and drinking (Holben et al., 1999; Amella, 2002). Regulations reflected in the Minimum Data Set define clinically significant problem eating as the consumption of less than 75% of one's meal (Simmons & Reuben, 2000). Similarly, studies evaluate fluid consumption to identify intake deficiencies, with a daily minimum of 1,500 to 2,000 mL of fluid considered protective against dehydration among long-term care residents (Holben et al.). Assuming that each resident's meal has been served in accordance with a dietary service plan, this proportionate definition allows comparisons across residents and settings.

Resident characteristics contributing to food and fluid intake include cognitive status (Young, Binns & Greenwood, 2001), ability to eat independently (Kayser-Jones & Schell, 1997), and physical limitations, such as difficulty swallowing (dysphagia; Steele, Greenwood, Ens, Robertson, & Seidman-Carlson, 1997). Care provision also contributes to intake, with up to half of residents requiring assistance (Priefer & Robbins, 1997), including monitoring, verbal encouragement, and physical assistance (Van Ort & Phillips, 1995; Kayser-Jones & Schell). Environmental characteristics contributing to adequate intake include food quality, absence of environmental distractions (e.g., noise), and noninstitutional features (e.g., tablecloths),

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as well as social interactions (Kayser-Jones & Schell; McDaniel, Hunt, Hackes, & Pope, 2001).

Despite what is known about correlates of adequate food and fluid intake among cognitively impaired residents of long-term care, no single study has examined these problems in residential care/assisted living (RC/AL; nonnursing home settings that provide room, board, assistance with activities of daily living [ADLs], and 24-hour oversight) or comprehensively considered these factors among a large sample. This study fills this gap by describing the multiple factors present during mealtime that are associated with low intake. Understanding these factors may help form strategies to increase food and fluid intake and reduce the incidence of malnutrition and dehydration in long-term care. While the primary purpose of this study is to assess resident, staff, and environmental characteristics associated with low food and fluid intake to further contextualize these factors, data also provide a description across different facility settings, including both nursing homes and RC/AL facilities.

Methods

Sample

Participants were recruited from 45 facilities across four states, including 35 RC/AL facilities and 10 nursing homes. A total of 421 residents aged 65 and older with diagnosed dementia were enrolled, with a participation rate of 73%. For details on the sample and methods of the Dementia Care Study, see Zimmerman, Sloane, Reed, and Williams (2005, this issue). In this analysis of low food and fluid intake, 407 residents were observed using the Structured Meal Observation.

Measures

The Structured Meal Observation (SMO).—The SMO was developed for the Dementia Care Study to provide a research tool capable of capturing resident experience during mealtime. The SMO draws from the Meal Assistance Screening Tool (MAST; Steele et al., 1997), and incorporates other items relevant to resident need, staff assistance, environmental context, and mealtime outcomes. The SMO, as used in these analyses, consists of 28 items and is administered by observing up to five residents during the course of a single meal. It was developed using an iterative process of literature review and consensus building among study investigators, yielding an instrument with good content validity and high interrater reliability (all items in these analyses had ≥ 70% agreement with only 4 [14%] having a kappa or intraclass correlation below 0.6, based on a sample of 48–56 paired observations). Structured meal observations were conducted by 10 data collectors, each of whom was a member of the research team and underwent training and interrater reliability testing on the SMO instrument.

In these analyses, the two outcomes of interest were amount of food and fluid consumed during a single meal, with low intake being ≤ 75% of food and ≤ 8oz. of fluid consumed. Other resident characteristics observed using the SMO included alertness (low/high), utensil use (low/high), and postural stability and movement (assessed dichotomously as per presence or absence of at least one of six types of movement/instability). The SMO also assessed several staff assistance variables and environmental features: whether staff provide monitoring, talk to the resident, and offer physical assistance; the number of staff that provide assistance relative to the number of residents in the room; whether residents eat in a dining area; noise level; food texture; if fluids are thickened; and the number of noninstitutional features present (e.g., not eating off a tray). Social environment items included the number of people grouped with the resident and presence of the resident's family.

Other resident characteristics.—Care supervisors reported whether or not a resident had at least one of 13 different mouth and throat problems, including dysphagia. Facility staff also provided data to determine residents' affect, behavior, activity involvement, and pain (Zimmerman et al., 2005). Cognitive status was assessed using either the resident's Mini-Mental State Exam score (Folstein, Folstein, & McHugh, 1975) or the supervisor-reported Minimum Data Set Cognition Scale (Hartmaier, Sloane, Guess, & Koch, 1994). Resident mobility was assessed through direct observation (Williams et al., 2005, this issue).

Facility characteristics and care.—The conceptual model underlying this study (Zimmerman et al., 2005) understands a resident's unmet need as the product of resident and care factors. Care factors under study include assessment of residents' difficulty eating and drinking, staff's perceived current status of residents' eating and drinking difficulties, treatment strategies employed by the staff to address eating and drinking difficulties, and the staff's perception of the success of the treatment provided. Additional facility characteristics reported by administrators include the proportion of direct care and supervisory staff with formal training in care of resident nutrition and hydration problems, facility ownership, and facility type.

Analyses

Bivariate linear and logistic regression models, with facility type as the independent variable, were estimated to assess differences between facility settings (i.e., RC/AL facility vs nursing home). Logistic regression models were used to estimate odds ratios and 95% confidence intervals for the association between resident and facility characteristics and each intake outcome. Multivariable models provided estimates adjusted for gender, race, age, cognitive status, comorbidities, and impairments in ADLs. All analyses were adjusted for facility clustering effects using

Table 1. Prevalence of Low Food and Fluid Intake and Relevant Components of Care in Dementia Care Study Sample, by Setting

| | % or M (SD) | | |
| | RC/AL | NH | |
Variable	(n = 276)	(n = 131)	p
Prevalence of low food and fluid intake			
Residents with low food intake	50.4	61.8	.046
Residents with low fluid intake	45.8	63.4	.011
Assessment of food and fluid intake			
Professional assessment for eating difficulty	32.5	66.7	.008
Written assessment for eating difficulty	26.1	43.3	.031
Professional assessment for drinking difficulty	34.6	63.2	.031
Written assessment for drinking difficulty	23.5	36.9	.200
Perceived presence of eating difficulty	11.0	19.6	.295
Perceived presence of drinking difficulty	5.5	10.2	.485
Mouth and throat problems	0.61 (1.3)	1.02 (1.6)	.101
Observed resident dependency			
Unresponsive or nonalert	4.4	2.3	.221
Poor utensil use	15.7	33.1	.020
Posture–movement problems	7.5	16.9	.057
Treatment of food and fluid intake			
Professionally treated for eating problems	7.1	30.2	.007
Informally treated for eating problems	15.6	34.9	.048
Professionally treated for drinking problems	5.2	22.6	.055
Informally treated for drinking problems	8.7	26.4	.040
Perceived success (if eating problem; quite a bit or extremely)	58.6	60.0	.825
Perceived success (if drinking problem; quite a bit or extremely)	65.0	65.6	.375
Observed staff assistance during meal			
Residents monitored	87.3	73.6	.227
Residents verbally encouraged	37.1	47.2	.185
Residents physically assisted	26.7	44.3	.045
Residents per staff	8.2 (7.4)	4.7 (3.1)	.005
Observed environmental characteristics			
Residents eating in dining area	96.7	81.5	.038
Noninstitutional features	3.7 (1.49)	2.0 (1.36)	< .001
Low noise level	51.6	35.1	.029
Pureed food	6.9	26.7	.007
Residents receiving thickened fluids	3.7	9.2	.170
Family present	5.4	9.3	.337
Number of residents grouped together	3.3 (1.5)	3.6 (4.9)	.803
Training to detect and treat eating problems[a]			
Supervisory staff			
None in facility	15.7	2.2	
Some in facility	7.7	36.5	
Most (≥ 75%) in facility	76.6	61.31	.576
Direct care providers (% in facility)			
None	16.4	2.2	
Some	11.7	0	
Most (≥ 75%)	71.9	97.8	.051
Staff feels adequately trained to assess	88.8	94.9	.582
Staff feels adequately trained to treat	87.0	91.2	.735
Training to detect and treat drinking problems[a]			
Supervisory staff (% in facility)			
None	25.9	25.6	
Some	11.3	36.5	
Most (≥ 75%)	62.8	37.9	.879
Direct care providers (% in facility)			
None	24.5	25.6	
Some	15.3	0	
Most (≥ 75%)	60.2	74.5	.403

(Table continues on next page)

Table 1. (*Continued*)

	% or *M* (*SD*)		
Variable	RC/AL (*n* = 276)	NH (*n* = 131)	*p*
Staff feels adequately trained to assess	79.9	95.6	.270
Staff feels adequately trained to treat	82.3	90.5	.522

Notes: SMO = structured meal observation; RC/AL = residential care/assisted living; NH = nursing home. Low food and fluid intake were assessed by observation using the SMO, and refer to ≤ 75% of food and ≤ 8 oz. of fluid consumed. Except as noted for training, all data are resident level and are for those residents observed using the SMO. Due to missing data, *n* varies from 203 to 276 for RC–AL and 87 to 131 for NH, except in the case of perceived success of treatment, which is relevant only for those with reported eating and drinking difficulties and for whom there are data for 58 (25%) and 45 (41.6%) RC–AL and NH participants, respectively, for eating difficulties and 40 (17.2%) and 32 (29.9%) RC–AL and NH participants, respectively, for drinking difficulties. *p* values are based on score statistics and were adjusted for facility-level clustering using generalized estimating equations (exchangeable correlation matrix).

[a]Data regarding supervisory staff training and direct care provider training are facility level and reported by administrators. Staff feelings of training adequacy are reported by the one supervisor (or direct care provider if supervisor data are missing) who is most involved in the resident's care; adequately is quite or extremely well trained.

generalized estimating equations (GEE), and an exchangeable correlation structure (Stokes, Davis, & Koch, 2000). Interactions of predictors with facility setting also were tested to confirm that factors' associations with food and fluid intake did not differ between nursing homes and RC/AL.

Results

The mean age of the 407 cognitively impaired long-term care residents observed for these analyses was 85 years old; 21% were males; and 11% were non-White. Approximately 37% of the residents had very severe cognitive impairment, while 27% had severe, 25% had moderate, and 12% had mild cognitive impairment.

The prevalence of low intake observed in this study was 54.1% (food, ≤ 75% consumed) and 51.3% (fluid, ≤ 8oz. consumed). As shown in Table 1, a significantly lower proportion of RC/AL residents had low food and fluid intake relative to those living in nursing homes (50.4% vs 61.8%, 45.8% vs 63.4%, respectively, *p* < .05). Several components of assessment and resident status differed by setting. RC/AL residents were significantly less likely to be assessed for eating and drinking difficulties, with assessment twice as prevalent in nursing homes. Treatment varied across settings as well. RC/AL residents were less likely to receive treatment for eating difficulty, either formally, for example by a professional (7.1% vs 30.2%, *p* = .007), or informally (15.6% vs 34.9%, *p* = .048). Further, staff were observed providing physical assistance to a higher proportion of residents in nursing homes (44.3%) versus RC/AL facilities (26.7%; *p* = .045). In addition, the number of residents per staff member providing care was lower in nursing homes, with an average of 4.7 versus 8.2 residents per staff member (*p* = .005).

Characteristics of the physical environment also differed by facility setting. More residents had meals in dining areas in RC/AL living (96.7% vs 81.5%, *p* = .038), and these areas had, on average, more non-institutional features (*p* < .001). The proportion of residents in a low-noise environment was higher in RC/AL (51.6% vs 35.1%, *p* = .029), and only 6.9% of RC/AL residents received pureed food, versus 26.7% in nursing homes. Additionally, administrators reported a higher proportion of direct care staff in nursing homes were trained to assess and treat eating difficulties, with 97.8% reporting most were trained versus 71.9% in RC/AL facilities (*p* = .051).

Table 2 displays risk factors for low intake, limited to a smaller sample (*n* = 326–335) of residents with complete data on factors used as covariates. The characteristics of this smaller sample did not differ in respect to age, gender, race, or cognitive status. After adjustment, only one resident characteristic was associated with low food intake (i.e., being nonalert), and none were associated with low fluid intake. Facility type was associated with intake, with residents of small RC/AL facilities less likely to have low food intake (OR = 0.26; 95% CI = .10, .65) and residents of new-model RC/AL facilities less likely to have low fluid intake (OR = 0.46; 95% CI = .27, .79). Ownership status also was related to both outcomes: Residents of for-profit facilities were less likely to have low food intake (OR = 0.29; 95% CI = .15, .57) and low fluid intake (OR = 0.34; 95% CI = .22, .53).

While formal assessment was not related to intake, residents monitored by staff were less likely to have low food intake (OR = 0.37; 95% CI = .18, .76) and low fluid intake (OR = 0.25; 95% CI = .12, .55). Also, a higher number of residents per staff member was linked to poorer fluid intake before and after adjustment (OR = 0.95; 95% CI = .91, .99). Finally, supervisor reports of treatment success were related to better fluid intake (OR = 0.30; 95% CI = .09, .94).

Two environmental features were significantly associated with both food and fluid intake. Residents having meals in the facility dining area rather than in their bedrooms were less likely to have low food intake (OR = 0.17; 95% CI = .04, .73) and low fluid intake (OR = 0.18; 95% CI = .06, .63). Similarly, residents in dining areas with more noninstitutional features were less likely to have low food intake (OR = 0.84; 95% CI = .72, .97) and low fluid intake (OR = 0.65;

Table 2. Characteristics Associated With Low Food (n = 335) and Fluid Intake (n = 326), Unadjusted and Adjusted

Characteristic[b]	Distribution of Characteristic as % or M (SD)				Relationship Between Characteristic and Presence of Low Food Intake		Relationship Between Characteristic and Presence of Low Fluid Intake	
	Food Intake		Fluid Intake		Unadjusted OR (95% CI)	Adjusted[a] OR (95% CI)	Unadjusted OR (95% CI)	Adjusted[a] OR (95% CI)
	Low (n = 176)	High (n = 159)	Low (n = 167)	High (n = 159)				
Resident								
Cognitive status								
Mildly impaired	8.6	16.9	10.9	14.2	1.00	1.00	1.00	1.00
Moderately impaired	30.5	22.1	23.8	29.0	0.98 (0.93, 1.05)	1.00 (0.93, 1.07)	0.95 (0.89, 0.99)	0.96 (0.89, 1.02)
Severely impaired	24.1	25.9	22.6	28.4	0.97 (0.86, 1.09)	1.00 (0.87, 1.53)	0.89 (0.80, 0.99)	0.92 (0.80, 1.05)
Very severely impaired	36.8	35.1	42.7	28.4	0.95 (0.79, 1.14)	1.00 (0.82, 1.24)	0.85 (0.72, 0.99)	0.87 (0.72, 1.07)
Depressed	22.3	24.3	25.3	19.9	0.89 (0.54, 1.48)	0.76 (0.48, 1.21)	1.67 (0.97, 2.88)	1.46 (0.83, 2.56)
Low activity	47.7	46.4	48.2	45.9	0.94 (0.61, 1.45)	0.95 (0.59, 1.51)	0.85 (0.55, 1.31)	0.80 (0.52, 1.24)
High pain	21.1	19.9	21.4	18.1	1.06 (0.51, 2.19)	0.92 (0.44, 1.92)	1.21 (0.64, 2.29)	1.17 (0.62, 2.24)
Immobile	14.9	8.1	15.2	7.9	2.23 (1.12, 4.45)	1.96 (0.92, 4.17)	2.19 (0.84, 5.72)	1.93 (0.69, 5.40)
Behavioral symptoms	61.5	54.1	60.5	55.6	1.34 (0.79, 2.26)	1.45 (0.85, 2.47)	1.10 (0.66, 1.85)	1.03 (0.62, 1.71)
Unresponsive or nonalert	5.8	0.7	4.9	1.9	8.02 (0.99, 64.95)	7.10 (1.09, 49.09)	2.33 (0.77, 7.08)	1.96 (0.58, 6.62)
Poor utensil use	21.4	19.6	26.9	13.6	1.06 (0.54, 2.06)	0.75 (0.36, 1.55)	2.19 (1.14, 4.22)	2.09 (0.89, 4.88)
Posture or movement problems	10.9	10.4	11.4	9.3	1.02 (0.53, 1.98)	0.92 (0.47, 1.79)	1.09 (0.53, 2.24)	0.91 (0.42, 1.98)
Facility								
Facility type								
NH	37.4	22.7	37.2	20.0	1.00	1.00	1.00	1.00
RC/AL, < 16 beds	7.5	20.1	14.0	13.6	0.32 (0.12, 0.82)	0.26 (0.10, 0.65)	1.10 (0.52, 2.38)	1.08 (0.48, 2.45)
RC/AL, traditional	20.7	24.0	20.7	24.5	0.83 (0.46, 1.49)	0.92 (0.49, 1.68)	0.79 (0.45, 1.44)	0.83 (0.44, 1.55)
RC/AL, new model	34.5	33.1	28.1	41.9	1.11 (0.68, 1.79)	1.18 (0.70, 1.98)	0.48 (0.30, 0.78)	0.46 (0.27, 0.79)
Facility size (OR per 10 beds)	92.9 (51.2)	76.8 (51.8)	85.4 (54.7)	84.6 (49.5)	1.08 (1.03, 1.14)	1.09 (1.03, 1.16)	1.00 (0.95, 1.06)	1.00 (0.94, 1.07)
For-profit ownership	59.4	79.8	58.4	79.3	0.32 (0.19, 0.55)	0.29 (0.15, 0.57)	0.34 (0.23, 0.52)	0.34 (0.22, 0.53)
Assessment of low intake								
Professional	43.5	42.8	44.6	44.5	1.17 (0.74, 1.85)	1.07 (0.62, 1.87)	0.98 (0.55, 1.73)	0.87 (0.50, 1.49)
Written or standardized	33.3	29.5	28.5	27.8	1.31 (0.74, 2.30)	1.21 (0.68, 2.16)	1.01 (0.57, 1.77)	0.94 (0.53, 1.65)
Perceived presence, current	14.6	11.1	6.5	5.9	1.46 (0.68, 3.15)	1.04 (0.43, 2.52)	1.09 (0.42, 2.88)	0.95 (0.37, 2.46)
Mouth or throat problems	31.5	34.5	37.9	27.8	0.82 (0.53, 1.26)	0.72 (0.43, 1.18)	1.42 (0.85, 2.37)	1.39 (0.76, 2.57)
Treatment of low intake								
Professional	14.5	13.2	11.5	9.1	1.15 (0.51, 2.61)	0.86 (0.36, 2.03)	1.18 (0.65, 2.16)	1.06 (0.56, 2.01)
Informal	21.7	20.4	15.8	12.9	1.13 (0.64, 1.99)	0.93 (0.44, 1.95)	1.13 (0.65, 1.97)	0.96 (0.49, 1.89)
Monitored	78.2	90.9	76.2	92.9	0.39 (0.19, 0.80)	0.37 (0.18, 0.76)	0.28 (0.13, 0.57)	0.25 (0.12, 0.55)
Verbally encouraged	47.9	30.9	43.5	36.9	2.14 (1.15, 4.01)	2.28 (1.16, 4.24)	1.21 (0.68, 2.15)	1.05 (0.51, 2.17)
Physically assisted	35.8	28.9	38.4	26.8	1.35 (0.74, 2.47)	1.26 (0.66, 2.43)	1.48 (1.00, 2.18)	1.39 (0.77, 2.50)
Residents per staff	7.0 (6.9)	7.8 (7.3)	6.1 (5.1)	8.8 (8.5)	0.98 (0.95, 1.01)	0.98 (0.95, 1.01)	0.95 (0.91, 0.99)	0.95 (0.91, 0.99)
Perceived success (if intake perceived low)	60.8	65.6	55.2	76.7	0.82 (0.31, 2.19)	0.92 (0.29, 2.82)	0.35 (0.11, 1.09)	0.30 (0.09, 0.94)

(Table continues on next page)

Table 2. (*Continued*)

Characteristic[b]	Distribution of Characteristic as % or M (SD)				Relationship Between Characteristic and Presence of Low Food Intake		Relationship Between Characteristic and Presence of Low Fluid Intake	
	Food Intake		Fluid Intake		Unadjusted	Adjusted[a]	Unadjusted	Adjusted[a]
	Low (n = 176)	High (n = 159)	Low (n = 167)	High (n = 159)	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)
Environment								
Residents in dining area	90.8	98.7	91.5	98.7	0.18 (0.05,0.62)	0.17 (0.04, 0.73)	0.18 (0.05, 0.69)	0.18 (0.06, 0.63)
Noninstitutional features	3.1 (1.6)	3.4 (1.5)	2.8 (1.6)	3.7 (1.4)	0.84 (0.73, 0.97)	0.84 (0.72, 0.97)	0.68 (0.58, 0.79)	0.65 (0.55, 0.77)
Low noise level	47.9	42.9	45.4	46.5	1.14 (0.68, 1.89)	1.32 (0.79, 2.20)	0.86 (0.42, 1.76)	0.92 (0.44, 1.89)
Pureed food	12.9	11.7	NA	NA	0.87 (0.34, 2.21)	0.65 (0.23, 1.79)	NA	NA
Fluids thickened	NA	NA	6.3	5.2	NA	NA	NA	NA
No. in residents group	3.3 (3.3)	3.8 (3.3)	3.8 (4.4)	3.3 (1.5)	0.96 (0.88, 1.05)	0.96 (0.89, 1.05)	1.02 (0.92, 1.14)	1.03 (0.93, 1.15)
Family present	5.2	7.8	6.7	5.8	0.45 (0.14, 1.44)	0.41 (0.12, 1.35)	1.49 (0.69, 3.27)	1.22 (0.46, 3.20)
Training to Detect and Treat[c]								
Supervisory staff								
None in facility	8.2	20.1	26.7	28.0	1.00	1.00	1.00	1.00
Some in facility	18.8	15.4	20.5	14.7	0.89 (0.83, 0.96)	0.89 (0.84, 0.96)	1.00 (0.93, 1.07)	1.01 (0.94, 1.08)
Most in facility ($\geq$ 75%)	72.9	64.4	52.8	57.3	0.81 (0.69, 93)	0.80 (0.70, 0.92)	1.00 (0.86, 1.16)	1.02 (0.89, 1.16)
Direct care providers								
None in facility	8.2	21.5	26.1	26.7	1.00	1.00	1.00	1.00
Some in facility	11.8	6.0	9.9	9.3	0.89 (0.84, 0.96)	0.89 (0.84, 0.96)	0.99 (0.93, 1.07)	0.99 (0.93, 1.07)
Most in facility ($\geq$ 75%)	80.0	72.5	63.9	64.0	0.81 (0.69, 0.93)	0.80 (0.70, 0.92)	1.99 (0.86, 1.15)	0.99 (0.87, 1.14)
Staff feels trained to assess	95.4	92.8	85.8	78.4	1.28 (0.40, 4.07)	1.72 (0.53, 5.59)	1.17 (0.62, 2.18)	1.12 (0.56, 2.25)
Staff feels trained to treat	92.5	88.9	85.4	79.9	1.05 (0.43, 2.55)	1.33 (0.54, 3.28)	1.02 (0.49, 2.11)	1.12 (0.52, 2.34)

Notes: NH = nursing home; RC/AL = residential care/assisted living; SMO = structured meal observation. Low food and fluid intake were assessed by observation using the SMO and refer to $\leq$ 75% of food and $\leq$ 8 oz. of fluid consumed. Except as noted for training, all data are resident level, are of those residents for whom outcome data (i.e., food and fluid intake) and supervisor data (required for adjustment) are available and are from supervisor report. Due to missing data, *n* varies from 238 to 298, except in the case of perceived success of treatment, which is relevant only for those for whom the staff perceives low food or fluid intake and for whom there are data for 81 (24%) of residents for food and 56 (17%) for fluid.

[a]Adjusted for male gender, non-White race, age, marital status, cognitive status, number of 11 comorbidities (congestive heart failure; high blood pressure or hypertension; myocardial infarction, heart attack, angina, arrhythmias, or other heart problem; diabetes; kidney disease or renal insufficiency; arthritis, rheumatism, degenerative joint disease, lupus, erythematosis, or scleroderma; fractured bones or osteoporosis; cerebrovascular disease, stroke, TIA, or CVA; hemiplegia or paraplegia; asthma, emphysema, bronchitis, or COPD; schizophrenia, manic-depressive disorder, or mental retardation), and impairments in seven activities of daily living (bed mobility, transfer, locomotion, dressing, eating, toilet use, hygiene).

[b]Cognitive status was based on Mini-Mental State Examination (MMSE) or Minimum Data Set–Cognition Scale (MDS-COGS) scores if the MMSE is missing (*n* = 51). MMSE cutpoints for mild, moderate, severe, and very severe are $\geq$ 18, 11–17, 3–10, 0–2; respectively; MDS-COGS cutpoints are 0–1, 2–3, 5–8, 9–10, respectively; depressed: $\geq$ 7 on the Cornell Scale for Depression in Dementia; low activity: < 9 (median) on the Albert Patient Activity Scale; high pain: $\geq$ 2 on the Philadelphia Geriatric Center Pain Intensity Scale; immobile: no position or location changes observed during 3 hours of observation; behavioral symptoms: any behavior at least weekly on the Cohen-Mansfield Agitation Inventory. Depression and behavioral symptoms are taken from supervisor report, activity is taken from care provider report, pain is taken from resident report, and immobility is based on direct observation.

[c]Data regarding supervisory staff training and direct care provider training are facility level and reported by administrators. Staff feelings of training adequacy are reported by the one supervisor (or direct care provider if supervisor data are missing) who is most involved in the resident's care; adequately is quite or extremely well trained.

95% CI = .55, .77). No differences were discovered in analyses of the interactions of these characteristics with facility type (RC/AL vs nursing home).

Discussion

As found by others (Kayser-Jones, Schell, Porter, Barbaccia, & Shaw, 1999; Keller, 1993), this study shows that prevalence of low food intake (54%) and low fluid intake (51%) is high among residents of long-term care, specifically among those with cognitive impairment. While these figures are lower in RC/AL facilities than in nursing homes, they still average approximately 50% overall. There are, however, noticeable differences between this observed prevalence and facility staff-reported prevalence of eating difficulties (13.7%) and drinking difficulties (6.9%). This discrepancy may exist because of underrecognition of problems or because the threshold of concern applied by facility staff is higher than that captured by the observation of one meal or using these cut points. However, the prevalence of low intake found through this study's observations are comparable to other observations of intake during a meal that used a similar indicator of inadequacy (Kayser-Jones et al.; Keller), suggesting the difference is one of underrecognition.

While nursing homes are more likely to assess and treat residents, residents in small RC/AL facilities have better food outcomes, and those in new-model RC/AL facilities have better fluid outcomes. Differences in staff assistance during meals and in the mealtime environment may contribute to disparate outcomes across facility settings. Residents monitored by staff during mealtimes are significantly less likely to have low food and fluid intake. Similarly, even after adjustment, residents having their meals in public dining areas are much less likely to have low intake relative to those in their bedrooms. Also, residents in dining areas with more noninstitutional features are less likely to have low food and fluid intake. Each of these beneficial staff and environmental conditions are more common in RC/AL settings.

Two aspects of this research should be noted. First, this is a study of food and fluid intake, not nutritional content. Thus, no nutritional information was used to evaluate food quality or food appropriateness relative to residents' nutritional needs. However, assessing the quantity consumed does provide an indicator that can be extrapolated into a measure of potential undernutrition and dehydration. Second, food and fluid intake during a single meal was recorded instead of overall resident intake levels throughout the day.

This study shows that across RC/AL facilities and nursing homes, there is a high prevalence of low food and fluid intake among cognitively impaired residents and a discrepancy between observed low intake and that reported by staff. While nursing homes report more assessment and treatment, outcomes do not relate to these, but instead are improved for RC/AL residents, who are more likely to be monitored during the meal, be in a public dining area, and be in a non-institutional-like setting. This research uncovers a potentially problematic care area in long-term care and highlights modifiable conditions that could be addressed through intervention. Staff who are more vigilant to low intake and facilities that attend to resident need and attempt to enhance the mealtime experience may improve nutrition and hydration among residents with dementia.

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Characteristics Associated With Lower Activity Involvement in Long-Term Care Residents With Dementia

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This article describes the characteristics associated with activity involvement in 400 residents with dementia in 45 assisted living facilities and nursing homes. Activity involvement was related to family involvement in care and staff encouragement, after adjusting for resident age, gender, race, cognitive and functional status, and comorbidity.

Key Words: Nursing homes, Assisted living, Residential care

There is evidence that engagement in meaningful social activities is related to quality of life for individuals residing in long-term care facilities (Gonzalez-Salvador et al., 2000; Hagen, Armstrong-Esther, & Sandilands, 2003). For example, participation in activities such as music, exercise, or cooking is associated with less depression, better cognition, mobility, and balance, and lower mortality rates (Kiely, Simon, Jones, & Morris,

2000; Koh et al., 1994; Marsden, Meehan, & Calkins, 2002; Mitchell & Kemp, 2000; Turner, 1993). Further, allowing residents choice in activity programming is associated with their involvement (Hedley, Wikstrom, Gunnarsson, & Sjoqvist, 1994). It is often a challenge, however, to involve persons with dementia in activities and for them to be able to inform facility staff of their preferences. This challenge may be especially notable in residential care/assisted living (RC/AL) facilities, which have become a predominant provider of long-term care. RC/AL facilities are nonnursing home residential settings that provide or arrange supportive and health care services for individuals who require assistance with daily activities (Kane & Wilson, 1993). Traditionally, they differ from nursing homes in that they promote a more social model of care (e.g., resident autonomy and choice in a home-like environment). Further, this social model of care, to which activity involvement clearly relates, is important to resident quality of life (Dobbs, 2004; Mitchell & Kemp, 2000; Zimmerman, Sloane, & Eckert, 2001). Given the difference in the RC/AL philosophy compared to nursing homes, these residents may have, and their families may expect them to have, higher activity involvement than residents in nursing homes (after adjusting for functional, cognitive, and health status). Thus, it is useful to understand resident involvement in activities and facility care related to resident involvement, both overall and separately, for each type of setting. Findings related to activity involvement, assessment for and availability of activities, and what resident and facility characteristics are associated with activity involvement may provide suggestions to improve care.

Research Design and Methods

Sample and Recruitment

The sample comprised participants in the Dementia Care project of the Collaborative Studies of Long-Term

Care (CS-LTC), living in a stratified sample of 35 RC/AL facilities and 10 nursing homes in Florida, Maryland, New Jersey, and North Carolina. In this study, RC/AL facilities included those facilities with fewer than 16 beds ($n = 14$); larger, traditional facilities ($n = 11$); and new-model facilities that tend to provide nursing care and/or cater to an impaired population ($n = 10$). Details of this typology can be found elsewhere (Zimmerman et al., 2001).

We randomly selected residents from among those aged 65 years or older who had a diagnosis of dementia. A total of 575 eligible residents were approached for enrollment. Of these, 421 (73%) agreed to participate, 66 (11%) refused, and 88 (15%) were unable to provide consent and had family members who were unreachable.

Data Collection

Data collection occurred between September 2001 and February 2003. For each resident, we conducted on-site interviews with the resident, the direct care provider who provided the most hands-on care and knew the most about the resident's care, health, mood, and daily activities, and the supervisor (i.e., staff member above a direct care provider level who knew the most about the resident). The facility administrator provided facility-level data, and the family provided information about their level of involvement in care. Further details about the Dementia Care sample and data collection procedures can be found in the introduction to this issue.

Measures

Activity involvement.—We measured activity involvement using the Patient Activity Scale–Alzheimer's Disease (PAS-AD; Albert et al., 1996), which was reported for each resident by the direct care provider ($n = 400$) as well as by self-report for residents ($n = 99$) scoring 10 or higher on the Mini-Mental State Exam (MMSE; Folstein, Folstein, & McHugh, 1975). We selected the PAS-AD because it includes activities judged to be within the capacity of demented individuals who receive supervision and aid in daily activities (Albert et al.; Logsdon, Gibbons, McCurry, & Teri, 1999). The 15 items include 5 that involve travel outside of the facility (e.g., going shopping, to church, for a car ride, to the movies, and to see family and friends) and 10 that can be carried out in the facility (e.g., being with pets, exercising). Each activity is rated for opportunity (yes/no) and engagement during a one-week time frame. Response categories for engagement are frequently ($\geq$ 3 times/week $= 2$), occasionally (1–2 times/week $= 1$), or never (0). Responses are aggregated into a summary activity measure, (range $= 0$–30), with higher scores indicating more activity. Because norms for the frequency of such activities among demented people do not exist, Albert and colleagues recommends defining "higher" and "lower" activity based on those above and below the median of the distribution. Hence, lower activity involvement is defined here as less than 9.0 for both care provider and resident respondents, which is the same cutpoint used by Albert and colleagues. Internal consistency for the PAS-AD was very good ($\alpha = 0.79$ and 0.80 for care provider and resident, respectively) and interrater reliability (care provider only, $n = 18$ pairs) was excellent (0.95 intraclass correlation coefficient for continuous measure and $K = 1.00$ for dichotomous measure of lower activity involvement).

Resident characteristics.—We categorized dementia severity as mild, moderate, severe, and very severe based on scores from the MMSE and Minimum Data Set Cognition Scale (MDS-COGS; Hartmaier, Sloane, Guess, & Koch, 1994). MMSE category ranges are $\geq$ 18, 11–17, 3–10, 0–2 respectively; MDS-COGS cutpoints are 0–1, 2–3, 5–8, 9–10. We measured depression using the Cornell Scale for Depression in Dementia (CSDD; Alexopoulos, Abrams, Young, & Shamoian, 1988); behavioral symptoms with the Cohen-Mansfield Agitation Inventory (CMAI; Cohen-Mansfield, 1986); and pain using the Philadelphia Geriatric Center Pain Intensity Scale (PGC-PIS; Parmelee, Katz, & Lawton, 1991). We measured immobility by direct observation (Williams et al., 2005, this issue). We measured low food intake using the Structured Meal Observation (SMO; Reed, Zimmerman, Sloane, Williams, & Boustani, 2005, this issue). We measured functional status using the Minimum Data Set–Activities of Daily Living (MDS-ADL; Morris, Fries, & Morris, 1999) as a count of the number of disabilities (range $= 0$–7).

Facility characteristics.—We obtained facility type, ownership (nonprofit, for-profit), bed size, and activity provision on a facility level from the administrator. We asked administrators to what degree the facility provides and encourages resident participation in 10 activities common to long-term care (exercise, personal care, social, housekeeping, meal preparation, crafts, work-oriented, special events, sensory, and intellectual; Zgola, 1987), and we coded responses as either not/rarely (less than one day/week) or regularly.

We asked supervisors three resident-level questions related to assessment: whether or not the resident's ability to participate and preferences for participation were assessed by an activity director; or by a written assessment; and how involved family members were in determining resident activities (from 0 = not at all to 4 = extremely). Supervisors also reported whether anything was done to encourage involvement in activities that the resident preferred and was able to do (yes/no); how well they feel the facility has been able to involve the resident in activities suited to his or her abilities and preferences (from 0 = not at all to 4 = extremely); and how well trained they feel in identifying residents' preferences and abilities to participate in activities, and helping residents participate in activities, as well as to actually help residents participate in activities. Finally, families reported their own involvement in care (number of

hours/week spent visiting with or talking to the resident for social reasons).

Analysis

We computed simple descriptive statistics separately for RC/AL facilities and nursing homes. We used generalized estimating equations (GEE; Diggle, Heagerty, Liang, & Zeger, 2002) for the statistical comparison of these characteristics by setting, applied to linear or logistic (for continuous and binary characteristics, respectively) models and an exchangeable correlation structure with facility as the clustering variable. *P* values were based on score statistics (Boos, 1992). To examine the association between resident and facility characteristics and care provider report of activity involvement, we estimated odds ratios and 95% confidence intervals using a separate binary logistic regression model for each characteristic, controlling for clustering using GEE empirical standard error estimates and an exchangeable correlation matrix. We estimated adjusted odds ratios controlling for gender, race, age, cognitive status, number of comorbid conditions, and ADL dependencies. We repeated analyses using linear regression with the continuous PAS-AD as the dependent variable; results were very similar, and only the logistic regression results are reported. We also tested interactions of predictors with setting.

Results

The mean age of the 400 residents was 84.7 years (range = 66–101 years), 20.0% were male, 9.5% were non-White, and 64.4% had severe or very severe cognitive impairment. Ninety-nine of the 400 residents with complete data on the outcome (24.7%) were sufficiently cognitively intact (scored ≥10 on MMSE) to report their own activity preferences and involvement. Based on supervisor report, slightly more nursing home residents exhibited lower activity involvement (56% vs 43%); this situation was reversed when reported by the 99 residents who could self-report (43% vs 55%); neither difference was statistically significant. As shown in Table 1, RC/AL residents enjoyed more activities than did nursing home residents based on staff report (10.7 vs 9.3, $p = .025$); no such difference was found for the 99 residents who could self-report (12.4 vs 13.0, $p = .319$). Based on staff report, the activities with the highest mean for both RC/AL and nursing home residents were (not shown) listening to radio, tapes or watching TV (1.49 and 1.62, respectively, on a scale of 0–3). Going shopping had the lowest mean (0.16 and 0.04), and 86.6% of RC/AL residents and 95.5% of nursing home residents had not gone shopping at all in the last week. Staff reported a high percentage of residents in both RC/AL facilities and nursing homes getting together with family and friends at least once in the last week (78.5% and 70.5%), but relatively few (33.6% of RC/AL residents and 16.2%

of nursing home residents) had spoken on the telephone. Further, 31.5% of RC/AL residents versus 12.0% of nursing home residents had been outside often in the last week. The differences between RC/AL and nursing home residents for this finding was significant ($p = 0.021$).

The percentage of residents assessed for ability and preferences were similar, with roughly one half of residents professionally assessed in RC/AL facilities and two thirds in nursing homes. Families were more involved in assessment in nursing homes compared to RC/AL facilities (2.0 vs 1.6, $p = .037$). RC/AL facilities and nursing homes were similar in the number of activities available (7.5 vs 8.2 out of 10), and while staff encouragement (as reported by supervisors) of resident involvement was slightly greater in nursing homes ($p = .078$), RC/AL staff believed treatment was successful for a higher proportion of residents (63% vs 50%), ($p = .067$). The majority of staff in both settings felt adequately trained.

Table 2 shows the distribution of characteristics related to lower activity involvement and the associated odds ratios and 95% confidence intervals. Lower activity involvement was more common in those with severe or very severe cognitive impairment, but this association was limited to nursing home residents and remained significant with adjustment for other resident characteristics (OR = 3.83; 95% CI = 2.69–5.45). Behavioral symptoms, depression, and ADL impairment were other resident characteristics associated with lower activity involvement, but the effects diminished in the adjusted model. Family involvement in assessing activities (OR = 0.86; 95% CI = 0.75–0.98), family social involvement (OR = 0.92; 95% CI = 0.87–0.97), and staff encouragement of activity involvement (OR = 0.32; 95% CI = 0.15–0.69) were all related to more activity involvement. Aside from cognitive impairment, there were no significant interactions between resident or facility characteristics and facility type (all were $p > .05$).

Discussion

The RC/AL facilities and nursing homes in this study did not differ in the number of activity types offered or in the level of involvement of residents with dementia. However, residents who self-reported were significantly more likely to indicate a higher number of activities *enjoyed* in RC/AL. In both settings, the residents who self-reported indicate a higher number of activities enjoyed compared to when staff reported for the larger sample. Other work has noted similarity in activity availability across settings (Zimmerman et al., 2003), but this is the first study to examine resident preferences, actual involvement of residents with dementia, and correlates of that involvement in both RC/AL facilities and nursing homes.

There were significant differences by facility type for activity involvement among residents who were more cognitively impaired: A higher percentage of

Table 1. Prevalence of Lower Activity Involvement and Relevant Components of Care in the Dementia Care Study Sample, by Setting

Activity Involvement	RC/AL ($N = 266$) % or M (SD)	NH ($N = 134$) % or M (SD)	p[a]
Prevalence of lower involvement			
Direct care provider report			
Involvement at or below median (9.0)	42.9%	56.0%	.125
PAS-AD score	9.8 (5.3)	8.3 (4.2)	.081
No. of 15 activities enjoyed	10.7 (3.4)	9.3 (4.2)	.025
Resident Report			
Involvement at or below median (9.0)	55.1%	42.9%	.491
PAS-AD score	9.1 (5.5)	10.0 (4.2)	.690
No. of 15 activities enjoyed	12.4 (2.7)	13.0 (2.0)	.319
Assessment			
Activity ability			
Activity director assessment	50.7%	77.1%	.355
Written or standardized assessment	34.3%	66.7%	.009
Activity preferences			
Professional assessment	53.1%	74.3%	.340
Written or standardized assessment	33.2%	54.3%	.062
Family involved in assessment	1.6 (1.4)	2.0 (1.3)	.037
Provisions and treatment			
No. of 10 types of available activities	7.5 (2.2)	8.2 (1.7)	.364
Staff encourages resident involvement	90.2%	97.6%	.078
Family involvement, social (hr/week)	4.3 (5.3)	4.7 (5.9)	.612
Perceived success (quite a bit or extremely)	63.2%	49.5%	.067
Training to facilitate activity participation[b]			
Staff feels adequately trained to assess			
preferences and abilities	77.5%	81.3%	.856
Staff feels adequately trained to help with participation	81.7%	82.1%	.378

Notes: RC/AL = residential care/assisted living; NH = nursing home; PAS-AD = Patient Activity Scale–Alzheimer's Disease. Lower activity involvement is defined based on a score below the median (9.0) on the PAS-AD. Except for number of activities available, all data are resident level and are for those residents for whom outcome data (i.e., activity involvement) are available. Direct care providers and residents (MMSE ≥ 10) provided data for the PAS-AD; supervisors reported on assessment, encouragement, and perceived success; administrators reported on activities available; feelings of training adequacy were reported by the one supervisor (or direct care provider, if supervisor data were missing) who was most involved in the resident's care; and level of family involvement (hr/week) was reported by resident's family. Due to missing data, N varies from 266 to 183 for residential care and assisted living and from 134 to 83 for nursing homes for care provider responses; for resident responses, $n = 78$ and $n = 21$, respectively.

[a]Adjusted for facility-level clustering using generalized estimating equations (exchangeable correlation matrix); p values are based on score statistics (Boos, 1992).

[b]Adequately is quite or extremely well trained.

nursing home residents compared to RC/AL residents with more severe cognitive impairment had lower activity involvement. Recognizing that these are adjusted activities, nursing home providers may gain insight from RC/AL facilities about how they are engaging these individuals in activities. Perhaps it is related to the social model of care philosophy that RC/AL facilities incorporate in their care practices.

Increased resident activity participation was associated with two measures of family involvement: the amount of time the family reports being socially engaged with the resident and the family's degree of involvement in assessing resident preferences as reported by the supervisor. Nursing home families were more likely to be involved in the assessment process (2.0 vs 1.6, $p = .037$). There is indication that it may be worthwhile to include families in the assessment process. In addition, when staff reported encouraging resident participation, the odds were higher that residents were more involved in activities.

Of course, in a cross-sectional study such as this, a causal ordering of events cannot be established. It is possible that staff encouragement and family involvement correlates with more social residents. The fact that family involvement and staff encouragement relate to activity involvement could be tested to target resident participation in some of the activities with low involvement mentioned in this article (going outside, shopping, and talking on the telephone with family and friends). That this effort might be worthwhile is supported by reports that these are viewed by many residents as key to quality of life (Dobbs, 2004).

Nonetheless, one limitation of this study is worth reporting. It relied on staff data for the outcome variable (because only a small number of residents were able to respond for themselves). While the measure used was designed for proxy report, and while proxies are useful when participants cannot respond for themselves, there is no gold standard against which to compare their reports.

Table 2. Characteristics Associated With Lower Activity Involvement, Unadjusted and Adjusted

Characteristics	Distribution of Characteristic as % or M (SD)		Relationship Between Characteristic and Presence of Lower Activity	
	Higher Activity Involvement (n = 174)	Lower Activity Involvement (n = 155)	Unadjusted OR (95% CI)	Adjusted[a] OR (95% CI)
Resident[b]				
Cognitive status				
Mildly impaired	17.8%	5.8%	1.00	1.00
Moderately impaired	28.7%	22.6%	1.64 (0.66–4.07)	1.37 (0.48–3.88)
Severe or very severe				
Cognitive impairment[c]				
RC/AL	50.0%	61.9%	1.42 (0.77–2.63)	1.09 (0.61–1.93)
Nursing home	62.5%	87.9%	4.82 (3.74–6.22)	3.83 (2.69–5.45)
Behavioral symptoms	55.0%	63.0%	1.65 (1.09–2.49)	1.35 (0.84–2.16)
Depressed	21.9%	26.7%	1.61 (1.08–2.40)	1.31 (0.85–2.02)
High pain	25.7%	15.2%	0.69 (0.40–1.19)	0.69 (0.39–1.23)
Immobile	12.8%	12.5%	0.97 (0.46–2.09)	0.76 (0.31–1.84)
Low food intake	52.9%	53.6%	0.80 (0.55–1.17)	0.81 (0.54–1.23)
Low fluid intake	50.9%	53.6%	0.83 (0.58–1.21)	0.80 (0.56–1.16)
ADL limitations	3.4 (2.5)	4.6 (2.3)	1.20 (1.07–1.35)	1.14 (1.00–1.28)
Facility				
Facility type				
Nursing home	27.6%	37.4%	1.00	
RC/AL				
< 16 beds	16.1%	12.3%	0.56 (0.23–1.41)	0.79 (0.31–1.96)
Traditional	25.9%	17.4%	0.47 (0.16–1.39)	0.68 (0.21–2.26)
New-model	30.5%	37.4%	0.85 (0.35–2.06)	1.16 (0.46–2.91)
For-profit ownership	77.0%	60.6%	0.53 (0.25–1.10)	0.58 (0.28–1.22)
Size (per 10 beds)	83.0 (48.9)	83.6 (58.4)	1.01 (0.94–1.07)	1.00 (0.93–1.06)
Assessment of activity involvement				
Activity ability assessed				
Professional	58.3%	61.4%	1.06 (0.63–1.78)	1.13 (0.60–2.13)
Written or standardized	41.7%	49.0%	1.07 (0.56–2.04)	1.13 (0.57–2.25)
Activity preferences assessed				
Professional	61.3%	59.7%	0.81 (0.44–1.49)	0.87 (0.44–1.71)
Written or standardized	36.9%	44.4%	1.10 (0.64–1.88)	1.12 (0.63–1.97)
Family involved in assessment	1.8 (1.4)	1.6 (1.4)	0.89 (0.78–1.01)	0.86 (0.75–0.98)
Provisions and treatment for activity involvement				
No. of 10 types of activities available	7.8 (1.9)	8.0 (1.8)	1.01 (0.81–1.27)	0.97 (0.77–1.22)
Staff encourages resident involvement	95.6%	89.0%	0.31 (0.13–0.74)	0.32 (0.15–0.69)
Family involvement, social (hr/week)	4.9 (6.0)	3.2 (4.1)	0.93 (0.88–0.98)	0.92 (0.87–0.97)
Perceived success	62.7%	54.5%	0.75 (0.42–1.35)	0.84 (0.47–1.50)
Training to facilitate activity participation[d]				
Staff feels adequately trained to assess preferences and abilities	82.2%	81.2%	0.77 (0.41–1.47)	0.82 (0.44–1.53)
Staff feels adequately trained to help with participation	84.5%	81.8%	0.78 (0.42–1.42)	0.87 (0.43–1.76)

Notes: RC/AL = residential care/assisted living; ADL = activity of daily living. For the table, N = 329. Lower activity involvement is assessed by direct care provider report on the Patient Activity Scale–Alzheimer's Disease and is based on the median value in the distribution (< 9). Except for facility demographics and number of activities, all data are resident level and are of those residents for whom outcome data (i.e., lower activity involvement) and supervisor data (required for adjustment) are available. Due to missing data, *n* varies from 137 to 174 for higher activity involvement and from 127 to 155 for lower activity involvement.

[a]Adjusted for gender, race, age, cognitive status, 11 comorbidities (congestive heart failure; high blood pressure or hypertension; myocardial infarction, heart attack, angina, arrhythmias, or other heart problem; diabetes; kidney disease or renal insufficiency; arthritis, rheumatism, degenerative joint disease, lupus, erythematosis, or scleroderma; fractured bones or osteoporosis; cerebrovascular disease, stroke, TIA, or CVA; hemiplegia or paraplegia; asthma, emphysema, bronchitis, or COPD; schizophrenia, manic-depressive disorder, or mental retardation), and impairments in 7 activities in daily living (bed mobility, transferring, locomotion, dressing, eating, toilet use, and hygiene), unless that is the predictor under study.

[b]Cognitive status is based on the Mini-Mental State Exam (MMSE) or Minimum Data Set–Cognition (MDS-COGS) scores, if the MMSE is missing (N = 54). Cut-points for mild, moderate, severe, and very severe (MMSE) are ≥ 18, 11–17, 3–10, 0–2, respectively; MDS-COGS cutpoints are 0–1, 2–3, 5–8, 9–10. Behavioral symptoms: any behaviors at least weekly on the Cohen-Mansfield Agitation Inventory; depression: ≥ 7 on the Cornell Scale for Depression in Dementia; pain: ≥ 2 on the Philadelphia Geriatric Center Pain Intensity Scale; immobility: no position or location changes observed during 3 hr of observation; low food intake and low fluid intake: consumed ≤ ³/₄ of meal and drank ≤ 8 oz. on Structured Meal Observation. Cognitive status and the MMSE are from resident report; depression, behavioral symptoms, pain, and ADL function are from supervisor report; and immobility and intake are based on direct observation.

[c]The association between cognitive impairment and activity involvement is reported separately for residential care and /assisted-living facilities and nursing homes because there is a significant Facility type × Cognitive impairment interaction (p = .007).

[d]Staff feelings of training adequacy are reported by the one supervisor (or direct care provider, if supervisor data are missing) who is most involved in the resident's care; "adequately" is quite or extremely well trained.

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Families Filling the Gap: Comparing Family Involvement for Assisted Living and Nursing Home Residents With Dementia

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Purpose: The purpose of this study was to compare the sociodemographics, self-rated health, and involvement levels of family caregivers of residents with dementia in residential care/assisted living (RC/AL) versus nursing home settings. **Design and Methods:** We conducted telephone interviews with the family caregivers most involved with 353 residents of 34 residential care and 10 nursing home facilities. We measured involvement by caregiver self-report of monthly out-of-pocket spending, involvement and burden ratings, and the frequency of engaging in eight specific care activities. Open-ended questions elicited areas in which caregivers preferred different involvement and ways the facility could facilitate involvement. **Results:** Nursing home caregivers rated their health poorer than RC/AL caregivers, but there were no sociodemographic differences between the two. RC/AL caregivers rated both their perception of involvement and burden higher and engaged more frequently in monitoring the resident's health, well-being, and finances than did nursing home caregivers, although the reported time spent per week on care did not differ. **Implications:** RC/AL and nursing home caregivers to residents with dementia may tailor their care to fit the needs of the resident and setting. Results are discussed in relation to the Congruence Model of Person-Environment Fit.

Key Words: Long-term care, Assisted living, Social support

Introduction

Families play an important role in the quality of care and quality of life of America's institutionalized elders. Among nursing home residents, family involvement has been associated with better psychological and psychosocial well-being (Greene & Monahan, 1982; McCallion, Toseland, & Freeman, 1999) and higher provision of certain types of treatment (Anderson, Lyons, & West, 2001). Higher life satisfaction has been reported for residential care–assisted living (RC/AL) residents who receive at least monthly visits from family (Mitchell & Kemp, 2000), and the quality of the social environment is important to resident satisfaction and feeling "at home" (Cutchin, Owen, & Chang, 2003; Sikorska, 1999).

Research suggests that it is especially vital to keep family members involved in the care of residents with dementia because they provide the historical background for residents, make care decisions, provide personal and social care, and are advocates for elders with dementia (McCallion et al., 1999; Port et al., 2001; Tornatore & Grant, 2002; Yamamoto-Mitani, Aneshensel, & Levy-Storms, 2002). However, many families try to avoid or delay nursing home care for their relatives with dementia by use of alternative forms of long-term care (Meyer, 1998), such as RC/AL settings. Given the value of family involvement for residents with dementia, an important component

in the placement decision should be the degree to which families are involved in care.

There is reason to expect family involvement to differ between RC/AL settings and nursing homes. Resident demographics, health care needs, and financing differ between these settings, with RC/AL facilities generally offering less intensive care to healthier and younger residents (Zimmerman et al., 2003) who are more commonly private pay than their nursing home counterparts. RC/AL facilities also market themselves as more homelike, permitting greater autonomy, choice, and privacy than nursing homes. Finally, the definition of assisted living of the Assisted Living Federation of America (ALFA, 1998) includes involvement of "the resident's family, neighbors, and friends" (p. 6). Thus RC/AL facilities may attract a different sociodemographic sector, include families to a greater degree in care, or include them in ways that are different than the involvement of families in nursing homes.

The current study addresses the need for basic information about family involvement for RC/AL residents with dementia and also how it compares to family involvement in nursing homes. Comparisons are made in terms of caregiver sociodemographics, self-reported health, and involvement. Involvement in care encompasses a wide range of activities, including hands-on care, financial monitoring, advocacy, care planning and decision making, family events and councils, interaction with facility staff, providing a connection with the past, social visits, and other forms of personal contact. While most previous research on family involvement in long-term care has used a single snapshot measure of involvement, namely visitation frequency (Port et al., 2003), this study includes a broad range of general and specific measures of involvement in order to provide a clearer picture of the similarities and differences for family caregivers in these settings. Because family involvement relates to resident needs and abilities (Barry & Miller, 1980; Yamamoto-Mitani et al., 2002), we conducted comparisons of involvement with and without controlling for resident and caregiver characteristics. We have also presented a comparison of areas in which caregivers would like more involvement and caregivers' suggestions for facilitating involvement.

Design and Methods

Sample

Participants in the Dementia Care project, a study of individuals with a diagnosis of dementia living in 35 RC/AL facilities and 10 nursing homes in four states (Florida, Maryland, New Jersey, and North Carolina), comprised the sample. Using the typology of the Collaborative Studies of Long-Term Care (CS-LTC), four types of facilities were enrolled: RC/AL facilities with fewer than 16 beds, traditional facilities, new-model facilities that tend to provide nursing care and/or cater to an impaired population, and nursing homes. RC/AL referred to all facilities licensed by the states at a nonnursing home level of care that provide room and board, assistance with activities of daily living (ADLs), personal care, medication administration, and 24-hour supervision or oversight. For purposes of efficiency, CS-LTC facilities with fewer than 2 eligible residents (in facilities with fewer than 16 beds) or 13 eligible residents (in all other facilities) were excluded. Eligible facilities were enrolled in a manner that maintained stratification across states and by facility type and that maximized the number of residents from smaller facilities. Twenty-two facilities (33%) declined to participate. These facilities did not differ from participating facilities in reference to type, size, or state. Of the final sample of 45 facilities, 14 (31%) had fewer than 16 beds, 11 (24%) were traditional facilities, 10 (22%) were new-model facilities, and 10 (22%) were nursing homes. Twelve facilities were from North Carolina, and all other states had 11 facilities.

Within study facilities, participants were randomly selected from residents aged 65 and older with a dementia diagnosis, to a maximum of four for smaller RC/AL facilities and 19 for all other facilities. Of 575 eligible residents approached for consent, 421 (73%) agreed to participate, 66 (11%) refused, and 88 (15%) could not provide consent and had unreachable family members. If available, one family member or friend who was most involved in care decisions for the resident and who visited or spoke with the resident or staff on his or her behalf was recruited by the study. These analyses were limited to the 353 participants for whom a family caregiver completed an interview and who resided in 34 RC/AL facilities and all 10 nursing homes. There was a mean of 11.9 caregivers from each nursing home (range 3–18) and a mean of 6.9 caregivers from each residential care facility (range 2–18). Data from residents and staff also were collected, as noted below. Further details about the CS-LTC and the sample and data collection for this study are provided in the introduction to this issue (Zimmerman, Sloane, Heck, Maslow, & Schulz, 2005).

Family Caregiver Interview

Family caregiver interviews lasted about 20 minutes and were conducted over the telephone between September 2001 and February 2003. In addition to providing sociodemographics (age, gender, race, kinship status, work status, education, income, number of dependents, months providing care, minutes to the facility), caregivers rated their current health (1 = poor, 2 = fair, 3 = good, 4 = very good, 5 = excellent). We rated income on a 1 to 5 scale (≤ 10,000; > 10,000 to < 20,000; > 20,000 to < 30,000;

> 30,000 to < 40,000; and > 40,000). In analyses, we dichotomized kinship into immediate kin (spouse, sibling, or child) versus extended kin and friends.

We measured involvement by having caregivers estimate the following:

1. Monthly out-of-pocket expenses spent toward resident care. These included facility rates, medical care costs, extras, transportation costs, and any additional services paid for, but did not include the resident's own out-of-pocket costs.
2. How much time per week the family caregiver spent visiting or talking with the resident for primarily social reasons.
3. Their current involvement, self-rated (1 = very high, 2 = high, 3 = average, 4 = low, 5 = very low).
4. Whether they preferred a different level of involvement than they had currently (1 = prefer to be much more involved, 2 = more involved, 3 = no change, 4 = less involved, 5 = much less involved).
5. How burdened they felt in caring for the resident (0 = not at all, 1 = a little bit, 2 = moderately, 3 = quite a bit, 4 = extremely).
6. Involvement in eight specific activities: visiting in person or taking the resident out; making phone calls or writing letters to the resident; doing the resident's laundry; assisting with ADLs (e.g., bathing, toileting, eating, dressing); assisting with instrumental ADLs (IADLs; e.g., shopping, errands, and cleaning); monitoring medical care (talking to staff, physician, or nurses about diet, medications, and health problems); monitoring well-being (speaking with staff about the resident's nonmedical care); and monitoring the resident's finances. Participants provided answers in terms of the number of times per day, week, month, or year, which were converted to monthly rates for analyses.

For caregivers who preferred a different level of involvement, we asked a follow-up, open-ended question: "In what way would you like to be more/less involved? What specific activities would you prefer to be doing more/less of?" Caregivers also were asked whether the facility should help them to be more involved in care. Of those who responded positively, we asked, "If the facility wanted to help you to be more involved in care, what could they do to help you with this?" Four coders placed responses to these open-ended questions into various categories. Initial coder agreement was 95% for the first question and 93% for the second question, and 100% consensus was obtained following coder discussion.

Resident Variables

We obtained functional status via interview with the care supervisor using the Miniumum Data Set–ADL (MDS-ADL; Morris, Fries, & Morris, 1999), as the number of seven activities in which the resident was not independent (bed mobility, transfer, locomotion, dressing, eating, toilet use, hygiene). Comorbidities was a count of the number of 11 conditions a resident had, including congestive heart failure; high blood pressure or hypertension; myocardial infarction, heart attack, angina, arrhythmias, or other heart problem; diabetes; kidney disease or renal insufficiency; arthritis, rheumatism, degenerative joint disease, lupus, erythematosis, or scleroderma; fractured bones or osteoporosis; cerebrovascular disease, stroke, TIA, or CVA; hemiplegia or paraplegia; asthma, emphysema, bronchitis, or COPD; and schizophrenia, manic-depressive disorder, or mental retardation. We assessed resident cognition by interview with the resident using the Mini-Mental State Exam (MMSE; Folstein, Folstein, & McHugh, 1975) and by interview with the care supervisor using the MDS Cognition Scale (MDS-COGS; Hartmaier, Sloane, Guess, & Koch, 1994). We classified cognitive deficits using established MMSE cutpoints ($\geq$ 17, 10–16, 3–9, 0–2) or MDS-COGS cutpoints if the MMSE was missing (0–1, 2–4, 5–6, 7–10).

Analytic Framework

We computed descriptive statistics of caregiver and resident characteristics separately for RC/AL facilities and nursing homes. We conducted statistical comparison of settings for population means (or proportions) of these characteristics using the generalized estimating equations (GEE) procedure to fit linear (or logistic) models for continuous (or binary) characteristics (Liang & Zeger, 1986; Preisser & Koch, 1997). Specifically, we used GEE based on an exchangeable correlation structure within facilities (clusters) to estimate means (and empirical or "robust" standard errors) by facility type while accounting for the correlation of outcomes among residents who cluster in facilities. It is well known that for a cluster-level covariate, such as facility type, failure to account for positive intracluster correlation in statistical comparisons of individual-level (resident-level) data results in inflation of Type I error (and p values that tend to be too small; Liang & Zeger, 1993). In a similar spirit, we conducted population-averaged comparison of measures of family involvement between residential care facilities and nursing homes with the general linear model with correlated errors (Diggle, Heagerty, Liang, & Zeger, 2002), specifying a compound symmetric correlation structure within facilities. We constructed two regression models for each involvement measure. The first model included only a fixed effect for facility type; we adjusted the second model for resident (cognitive function, ADL impairment, number of comorbid conditions, and age) and

Table 1. Characteristics of Family Caregivers in Residential Care/Assisted Living and Nursing Home Settings

Variable	RC/AL		NH	
	n (%)	X (SD; Range)	n (%)	X (SD; Range)
Caregivers				
Age	234	59.1 (12.0; 28–95)	119	58.7 (11.4; 37–87)
Gender				
Male	81 (34.6)		40 (33.6)	
Female	153 (65.4)		79 (66.4)	
Race				
Black	11 (4.7)		19 (16.0)	
White	222 (95.3)		100 (84.0)	
Kinship				
Non-1st degree	54 (23.1)		25 (21.0)	
1st degree	180 (76.9)		94 (79.0)	
Work				
Full or part time	135 (57.7)		67 (56.3)	
Not working	99 (42.3)		52 (43.7)	
Years of education	234	15.5 (2.8; 4–26)	119	14.8 (3.0; 4–24)
Income	193	4.4 (.96; 1–5)	104	4.1 (1.31; 1–5)
Self-rated health*	234	3.8 (1.04; 1–5)	119	3.5 (0.91; 1–5)
No. of dependents	234	.67 (1.11; 0–5)	118	.59 (0.91; 0–3)
Months providing care	215	81.8 (75.3; 2–468)	119	103.4 (94.7; 3–504)
Minutes to the facility	232	55.4 (114.2; 1–500)	119	52.1 (93.1; 1–500)

Notes: RC/AL = residential care/assisted living; NH = nursing home. For RC/AL, n = 193–234; for NH, n = 104–119.
*p < .05.

caregiver (health, income, education, age, and race) characteristics. Based on each fit, we computed model-predicted means of involvement measures and their cluster-adjusted standard errors for RC/AL and nursing homes to provide statistical comparisons of facility type. Because a substantial number of caregivers (n = 45) were missing data for family income but had data for all other residents and caregiver covariates, we used stochastic regression imputation based on a proportional odds regression model to generate an imputed value for income for these caregivers (Little & Ruben, 2002).

Results

Comparisons of Residents Included and Excluded From Analyses

Of the total sample enrolled in the Dementia Care project (n = 421), there were no significant differences between residents who did (353) and did not (68) have a family interview in terms of age, functional status, cognitive function, comorbidity, or facility type.

Caregiver Characteristics

Table 1 displays sample characteristics separately for RC/AL and nursing home caregivers. For the entire sample, the majority were female (65.7%) and White (91.5%), and the mean age was close to 60. The largest group was daughters or daughters-in-law (43.3%), followed by sons or sons-in-law (24.7%) and spouses (9.3%), and a small proportion (1.4%) was friends or neighbors. The RC/AL and nursing home caregivers differed significantly only in self-rated health, with RC/AL caregivers rating their health higher than nursing home caregivers (p = .026).

Resident Characteristics

There were no differences in resident age or number of comorbidities. RC/AL residents had a mean age of 85.1 (SD = 6.9; range 67–100), and nursing home residents had a mean age of 84.2 (SD = 7.1; range 67–101). RC/AL residents averaged 2.0 (SD = 1.5, range 0–7) comorbidities, compared to 2.4 (SD = 1.6, range 0–7) for nursing home residents. However, facility residents had significantly fewer areas of ADL impairment (3.4; SD = 2.4, range 0–7) than did nursing home residents (2.4; SD = 1.8, 0–7; p = .001). RC/AL residents were also significantly less cognitively impaired, having 13.3% mild, 28.8% moderate, 23.8% severe, and 29.2% very severe compared to nursing home residents with 8.0% mild, 13.3% moderate, 22.1% severe, and 56.6% very severe (p = .003).

General and Financial Involvement.—As shown in Table 2, RC/AL and nursing home caregivers reported spending approximately $500 and $400 dollars per month, respectively, on out-of-pocket costs. They also spent an average of 259 minutes

Table 2. Involvement for Family Caregivers of Residential Care/Assisted Living and Nursing Home Residents

Involvement Type	Unadjusted				Adjusted[a]			
	M	(SE)	t stat	p	M	(SE)	t stat	p
General measures of involvement								
Monthly out-of-pocket costs								
RC/AL	501.94	114.39	−0.47	.643	356.14	166.04	−0.65	.521
NH	401.33	182.67			215.51	213.13		
Weekly minutes spent visiting or talking								
RC/AL	259.12	23.94	−0.51	.616	283.53	41.87	−0.55	.582
NH	237.53	35.34			257.77	48.23		
Self-rated involvement								
RC/AL	2.31	0.05	4.46	< .001	2.12	0.16	2.82	.005
NH	2.72	0.08			2.62	0.18		
Involvement preference								
RC/AL	2.80	0.04	−3.57	< .001	2.73	0.07	−1.37	.177
NH	2.57	0.05			2.64	0.07		
Overall burden								
RC/AL	1.15	0.05	−2.48	.018	1.13	0.13	−2.55	.015
NH	0.92	0.08			0.80	0.14		
Involvement in specific activities (times per month)								
Visit or take resident out of facility								
RC/AL	9.72	0.68	−0.73	.473	10.82	1.30	−1.36	.182
NH	8.85	0.98			8.94	1.45		
Call on phone or write letters								
RC/AL	4.69	0.86	−2.16	.037	6.32	1.27	−0.96	.344
NH	1.37	1.28			5.05	1.41		
Laundry								
RC/AL	1.58	0.39	0.50	.620	2.38	0.61	0.26	.798
NH	1.93	0.58			2.55	0.68		
ADL assistance								
RC/AL	2.10	0.56	1.70	.097	2.02	0.94	0.55	.584
NH	3.82	0.84			2.62	1.11		
IADL assistance								
RC/AL	2.14	0.25	−2.20	.034	2.44	0.41	−1.54	.131
NH	1.12	0.39			1.70	0.49		
Medical monitoring								
RC/AL	5.81	0.86	−1.62	.114	6.26	1.70	−2.12	.040
NH	3.38	1.23			2.49	1.87		
Monitor well-being								
RC/AL	6.25	0.53	−1.31	.198	6.91	0.94	−2.32	.026
NH	5.04	0.76			4.55	1.06		
Monitor Finances								
RC/AL	5.27	0.44	−3.98	< .001	5.20	0.88	−3.98	< .001
NH	2.24	0.63			1.80	0.94		

Notes: RC/AL = residential care/assisted living; NH = nursing home; ADL = activity of daily living; IADL = instrumental activity of daily living. For the table, n = 280–290. Income values were imputed using stochastic regression imputation based on a proportional odds regression model (Little & Rubin, 2002).

[a]Adjustment for resident cognitive function, ADL impairment, number of comorbid conditions and age, and for caregiver health, income, education, age, and race.

(roughly 4.2 hr) and 237 min (4.0 hr) a week visiting or talking with the resident, respectively. These differences were not statistically significant. RC/AL caregivers rated their involvement and burden significantly higher than nursing home caregivers, and this difference persisted with adjustment for caregiver and resident characteristics. Finally, without adjustment, nursing home caregivers were more likely to prefer increased involvement; however this difference no longer reached significance following adjustment.

Frequency of Engagement in Specific Care Activities.—Prior to adjustment, the RC/AL caregivers made more phone calls to residents and more frequently assisted with IADLs; however, these differences were no longer statistically significant following adjustment for resident and caregiver characteristics. After adjustment, the caregivers to RC/AL residents engaged more frequently in medical monitoring, financial monitoring, and monitoring of the resident's well-being. We found no differences before or after adjustment for assisting with ADLs, visiting, or doing laundry. The unadjusted percent-

age of RC/AL and nursing home caregivers (respectively) who reported ever engaging in each specific activity was: visit or take out, 98.3% and 96.6%; phone call or letter, 42.4% and 28.6%; do laundry, 25.4% and 26.1%; assist with ADLs, 29.7% and 36.2%; assist with IADLs, 77.4% and 58.1%; monitor medical care, 90.8% and 92.4%; monitor well-being, 92.1% and 88.1%; and monitor finances, 90.4% and 75.4%.

Areas in Which Different Involvement is Desired.—Of the total sample, 4.3% preferred less involvement, 27.2% preferred more, and the remainder (68.6%) preferred no change. We asked those preferring greater involvement to specify the areas in which they would like to be more involved. For RC/AL caregivers, the largest group (41%) wanted to take the resident out more often to visit friends and family or for entertainment (e.g., shopping, dining). Typical responses were, "I'd like to take her places more if I had the time" and "Getting her out more, talking to her sisters." The next largest group (36%) stated only that they wanted to spend more time with the resident and did not specify further. Less frequent responses included monitoring care (7%), providing personal care (7%), having the resident come home to live with them (7%), and involvement in facility-offered activities (2%). For nursing home caregivers, the largest group (41%) wanted to spend more time with the resident without specifying further. The two next largest groups, at 22% each, wanted more involvement in monitoring care or taking the resident out of the facility. Less frequently cited responses included taking part in more activities (14%) and involvement in personal care (3%). Fifteen caregivers desired less involvement. When asked in what areas they sought to decrease involvement, we obtained 11 responses. Due to the low number of responses, we have not presented percentages; however, there appeared to be a trend for nursing home caregivers to prefer less involvement in personal care, while RC/AL caregivers preferred less involvement in paperwork and financial monitoring.

Areas in Which Caregivers Desire Assistance in Being Involved.—Approximately one quarter of the sample (22.4%) felt that the facility could do more to help them be more involved in care. Sixty-eight caregivers provided responses when we asked them to identify specific ways facilities could assist them; because the categories were identical and the proportions highly similar between the 44 RC/AL and 24 nursing home caregivers, we combined the results. Close to one half of respondents (44%) sought more frequent communication from the facility in terms of regular meetings, phone calls, or more consistent notification of change in the resident's status (e.g., "Call once or twice a week,

or some kind of contact that is more often"; "Better communication about his behavior—more information regarding his physical health"). One fifth of these requests specifically asked for a regular newsletter. The next largest group (13%) wanted organizational or administration changes such as more responsive staff, greater continuity of care among staff, improvements in staff numbers or qualifications, and more openness with families about problems at the facility. The same proportion (13%) felt the facility could be doing more, but did not have a specific suggestion. Other recommendations included greater involvement in activities at the facility (7%), opportunities to meet with other residents' families (7%), advice and encouragement regarding how they could be more involved (e.g., "Tell me what I need to do more because I don't know," "Maybe they could encourage me a little more"; 7%), more convenient scheduling of meetings (4%), and more interaction with physicians (3%).

Discussion

With the exception of self-rated health, we found no differences between the family caregivers to RC/AL and nursing home residents across several health and sociodemographic characteristics. Whether RC/AL caregivers actually have better health than their nursing home counterparts or tend to rate their health more positively, a relationship between the caregiver's self-perceived health and the long-term care setting is understandable. In most cases, and especially when the resident has dementia, family members conduct the search for and ultimately select the long-term care setting (Castle, 2003). The higher level of care in nursing homes may be preferred when the family caregiver's own health limits his or her ability to assist the resident with IADLs and other tasks provided for less in RC/AL care.

Examining the more detailed level of specific activity engagement suggests that these caregivers were tailoring their involvement to the specific abilities of the resident in his or her setting. For example, RC/AL caregivers more frequently contacted the resident via telephone or letter, provided assistance with IADLs, and monitored finances. Higher rates of calling and writing and assisting with IADLs likely reflect the higher functional ability of RC/AL residents, an interpretation supported by the finding that these comparisons lost significance after adjustment for resident health and function. The higher proportion of private pay clients in RC/AL and the variable cost structures of many facilities no doubt increase the amount of attention that families must give to the resident's financial situation.

We were particularly struck by the finding that RC/AL caregivers monitored the residents' medical status and well-being more frequently, despite a lack

of differences in visitation or time spent caring. By design, nursing homes provide more monitoring than RC/AL facilities. Thus, a resident placed in a nursing home may be viewed by family as receiving sufficient, or nearly sufficient, monitoring; leaving the family caregiver to devote more effort to other aspects of caring, such as providing entertainment or simply being with the resident. The same resident placed in an RC/AL facility may be viewed by family as receiving insufficient monitoring to maintain safety and/or well-being. In these instances, our data suggest that the caregiver steps in to make up the difference, checking the resident's medications, safety, mood, or other care needs depending on the resident's particular area(s) of vulnerability.

This does not imply that RC/AL facilities need to increase their monitoring role. This would defeat the purpose of these facilities as less restrictive alternatives to nursing homes; further, most residents probably prefer family, rather than staff, oversight. Research comparing RC/AL facilities and nursing homes on important clinical outcomes such as health and mental health, well-being, pain and discomfort, functioning, and staff–resident interaction has generally found few differences (Frytak, Kane, Finch, Kane, Maude-Griffin, 2001; Pruchno & Rose, 2000; Rose & Pruchno, 1999; Sloane et al., 2005, this issue). While additional research is needed, our findings support a view that the apparent lack of differences in clinical outcomes between RC/AL and nursing homes can be at least partially attributed to the diligent efforts of caregiving families. Likewise, to the extent that the lower costs of RC/AL are attributable to fewer staff and regulations, families may help make those lower costs possible.

This leads to an interesting twist on the well-known congruence model of person–environment fit (Kahana, 1982). The congruence model posits that individuals function optimally when environmental demands are appropriate to a person's abilities. The nursing home environment provides a high level of care that minimizes demands on the resident. In the RC/AL environment, the bar is set higher, so to speak, placing more demands on the resident. While the person–environment fit may be ideal for a proportion of residents in each facility type, there are likely nursing home residents who could function adequately with more environmental demands and RC/AL residents who need extra assistance. Families and staff in nursing homes report tensions when families interfere to too great a degree in the resident's care (Duncan & Morgan, 1994; Friedemann, Montgomery, Maiberger, & Smith, 1997), but the more flexible system of care provided by RC/AL facilities may tolerate (and perhaps even welcome) family "interference." As a result, RC/AL residents may enjoy the benefits of more independent living without assuming all of the additional risk such freedoms entail. In the context of RC/AL settings, person–environment fit may more accurately be described as "person–family–environment fit."

However, the higher level of monitoring provided by RC/AL caregivers appears to come at a price. Both with and without adjustment, these caregivers rate their involvement and burden higher than nursing home caregivers. Prior to adjustment, they were also less likely than nursing home caregivers to prefer greater involvement. Again, even though these caregiver groups report spending similar amounts of time on visits, they seem to experience that time differently. The RC/AL caregivers in our study felt more involved and more burdened than the nursing home caregivers, probably as a function of the greater personal responsibility they assume in order to maintain the resident's safety, well-being, and financial stability.

This is not to say that RC/AL caregivers want less involvement. When asked, only a very small percentage of the total sample (4.3%) preferred less involvement. But even if most wanted to increase (27.2%) or maintain (68.6%) their current level of involvement it should not be concluded that the caring situation for these families could not be improved. Most family caregivers in this and other samples have jobs, many have additional dependents, and some have their own serious health concerns (Brody, Dempsey, & Pruchno, 1990; Dempsey & Pruchno, 1993; Duncan & Morgan, 1994; Farber, Brod, & Feinbloom, 1991). Previous research has identified several factors related to higher family involvement, including closer kinship status, nonuse of Medicaid, and shorter duration of stay in the facility (Bitzan & Kruzich, 1990; Greene & Monahan, 1982; Port et al., 2001; Yamamoto-Mitani et al., 2002). Noting that these factors do not lend themselves well to improvement through intervention, recent research has identified more changeable barriers to involvement, including transportation difficulties, problematic family and staff relationships, and inadequate social support networks for caregivers (Port, 2004).

The open-ended questions in our study provide some direction for assisting family caregivers who desire greater involvement in care. As a group, nursing home caregivers were more focused on increasing involvement in facility-directed ways (e.g., facility-based activities and monitoring care) while RC/AL caregivers sought less facility-directed involvement, such as taking the resident out and providing care at home. At the same time, it is clear that the overall desire among these caregivers, regardless of setting, is to spend more time with the resident. Many caregivers acknowledged a need for more assistance from the facility but could not define that need. This finding, combined with those family caregivers who requested more advice and encouragement from the facility, attests to the need for families to receive more appreciation and education concerning the important role they play

in preserving the well-being of their loved ones (Laitinen & Isola, 1996). Additional research is needed toward understanding caregiver's desires for more and less involvement.

As with all studies, limitations must be acknowledged. Caregivers who agreed to participate may have been those who were more involved (Farber et al., 1991). However, there is no reason to suspect participation biases by facility type, as caregiver participation rates for RC/AL facilities and nursing homes did not differ. Therefore the comparison of involvement between facilities should be not be affected by the issue of participation. Self-reports of involvement could also lead to inflated estimates. While staff and resident reports of family involvement could have been used to collect these data, self-reported family involvement is the most commonly used approach (Port et al., 2003). Staff is not necessarily aware of family caregiver activities due to busy case loads and shift changes, and resident reporting is dependent on cognitive function, a critical issue in any study of residents with dementia. Also, neither staff nor residents could report accurately on caregiver tasks that take place away from the resident and facility, such as monitoring finances. Finally, the study may have had inadequate power to detect differences in variables that tended to cluster within facilities. Race may be one of those variables, considering that the p value approached statistical significance and differences have been found in the racial composition of RC/AL facilities versus nursing homes (Howard et al., 2002). Other possible examples for which a variable may have clinical significance even though it did not reach statistical significance include differences in out-of-pocket costs and minutes per week spent visiting or talking with the resident.

Despite these limitations, we note that the demographics as well as the visitation rates and duration of the nursing home caregivers in this sample are highly similar to previous nursing home family caregiver samples (Duncan & Morgan, 1994; Farber et al., 1991; Greene & Monahan, 1982; Ross, Carswell, & Dalziel, 2001; Whitlatch, Schur, Noelker, Ejaz, & Looman, 2001; Yamamoto-Mitani et al., 2002). The overall impression from this study is that while RC/AL residents with dementia may have more freedom than nursing home residents with dementia, their family caregivers feel somewhat less freedom compared to their nursing home counterparts. To the extent, then, that RC/AL facilities are successful in assisting America's elders to age in place, the families of these residents may be playing a critical role. Given willing and able family caregivers, this arrangement is probably the most desirable for all concerned. However, the contribution of families to these and other long-term care settings deserves more recognition and value within the larger society.

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Attitudes, Stress, and Satisfaction of Staff Who Care for Residents With Dementia

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Purpose: Considering the increasing proportion of residents in long-term care who have dementia, and the important influence that direct care providers have on resident quality of life, this study explores the dementia-related attitudes of residential care/assisted living (RC/AL) and nursing home staff, as well as their work stress and satisfaction. **Design and Methods:** Data were derived from interviews with 154 direct care providers from 31 RC/AL facilities and 10 nursing homes who participated in the Collaborative Studies of Long-Term Care. **Results:** Stress was more often reported by care providers who had been working for 1 to 2 years (compared with longer); in addition, those who had been working for 1 to 2 years were more likely to espouse hopeful or person-centered attitudes than those who had been working for a longer period of time. Also, a person-centered attitude related to satisfaction, and perceived competence in providing dementia care was consistently associated with dementia-sensitive attitudes and job satisfaction. **Implications:** Attending to the welfare and ongoing training of workers who have demonstrated job commitment may lessen their tendency to become jaded over time or seek job opportunities elsewhere. Further, the attitudes the staff hold related to dementia and the training they receive to provide dementia care are important for their own well-being.

Key Words: Long-term care, Assisted living, Nursing home, Alzheimer's disease

Direct care providers in long-term care facilities have a difficult job. Nurse aides and personal care aides work long hours, are poorly paid, receive minimal benefits, and are prone to injury and depression (Deutschman, 2000; Mercer, Heacock, & Beck, 1993; Schrim, Uhman, & Barton, 1996). Ironically, concomitant with these challenges is the recognition that these workers are central to resident quality of life, and that the relationship between the resident and caregiver is a central feature of this quality (Bowers, Esmond, & Jacobson, 2000). Thus, the approaches exhibited and stressors experienced by nurse aides and personal care aides are of importance for the well-being of not only the workers themselves, but also of the residents and families they serve. It may come as some surprise, then, that although there has been extensive research considering the stress of caring for people with dementia on family caregivers, little research has investigated the stressors placed on these long-term care workers (Mackenzie & Peragine, 2003; McCarty & Drebing, 2003). This oversight applies to care in both nursing homes—in which more than 50% of residents have dementia (Krauss & Altman, 1998)—and residential care/assisted living (RC/AL) settings, in which 24% to 42% of residents have moderate or severe dementia, including as many as 8% with severe dementia (Zimmerman & Sloane, 1999).

Matters related to care provision in RC/AL are particularly understudied, as this component of long-term care has only recently undergone significant

growth. RC/AL is broadly defined as those facilities (or discrete portions of facilities) licensed by the state, at a non-nursing-home level of care, that provide room, board, 24-hr oversight, and assistance with activities of daily living (Kane & Wilson, 1993). They display marked diversity, ranging from converted single-family homes with only a few resident beds to high-rise facilities with hundreds of beds. Between 15% and 37% of residents are impaired in three or more core dependencies (e.g., dressing, eating, and transferring), and 37% to 49% exhibit behavioral symptoms, with rates of impairment tending to be higher in smaller facilities (Zimmerman, Sloane, & Eckert, 2001; Zimmerman et al., 2003). As RC/AL has become a notable site of care for almost 1 million individuals (Golant, 2004), it is important that they be included when statements are made about the situation of the direct care provider in long-term care.

The theoretical model of stress in nursing home staff provides a helpful grounding for this topic. It recognizes sources of stress (personal and work stressors related to the overall function of the workplace and interactions with coworkers and residents), intervening variables (personal and work resources, the latter of which includes job training), the resultant person–job fit, the stress response (including emotional reactions such as cynicism or optimism and satisfaction, and behavioral reactions such as quitting), and the impact of stress on the workplace (related to the quality of care; see Cohen-Mansfield, 1995). Others agree that contributors to stress include lack of preparation to provide care and lower self-efficacy in perceived ability to provide care, and that the impact of stress includes decreased job satisfaction and increased turnover (Evers, Tomic, & Brouwers, 2001; Mackenzie & Peragine, 2003; Schaefer & Moos, 1996). As turnover rates exceed 100% in many long-term care settings (Pillemer, 1997), the time has come to better understand the attitudes, stressors, and satisfaction of direct care workers who provide care to those with dementia.

We designed this study to examine the attitudes that long-term care workers hold about dementia, the work stress they experience, and the satisfaction they derive from working with these residents. We explore differences by facility types and worker characteristics and examine (select) sources of stress, intervening variables, the resultant level of stress, and responses to stress. We conclude with suggestions on steps that might be taken to affect attitudes, stress, and satisfaction that have implications for the quality of care.

Methods

Participants and Recruitment

The facilities and staff participating in this project are part of the Collaborative Studies of Long-Term Care (CS-LTC), a consortium of more than 350 RC/

AL facilities and nursing homes across four states (Florida, Maryland, New Jersey, and North Carolina) that have been participating in studies related to quality of life and quality of care since 1997. Using the typology developed for the CS-LTC, the Dementia Care project enrolled four different types of facilities: nursing homes; RC/AL facilities with fewer than 16 beds; traditional RC/AL facilities; and new-model RC/AL facilities distinguished by provision of nursing care or that cater to an impaired population. Details of the CS-LTC and the facility typology can be found elsewhere (Zimmerman et al., 2001).

The Dementia Care project used a multistage cluster sampling strategy. It enrolled a purposive sample of 45 facilities, 33 of which were drawn from those already participating in the CS-LTC and known to evidence variability in some areas of dementia care (e.g., acceptance of behavior symptoms). Chapter representatives from the Alzheimer's Association identified 12 additional facilities that had some features of particular interest (e.g., responsive owners, a special care unit, individualized care, daily programming, staff training, or environment features). In general, we excluded facilities with fewer than 2 eligible residents (in facilities with fewer than 16 beds) or 13 eligible residents (in all other facilities) from the study. We enrolled all eligible facilities in a manner that maintained stratification across states and by facility type. During recruitment, 22 facilities (33%) refused to participate. Facilities that refused did not differ from participating facilities by type, size, or state. The final sample included 14 facilities with fewer than 16 beds (31% of the sample), 11 traditional RC/AL facilities (24%), 10 new-model RC/AL facilities (22%), and 10 nursing homes (22%). Proportionately more small facilities were enrolled to increase the number of residents and staff who represented that stratum. North Carolina had 12 facilities, and all other states had 11 facilities.

Within these facilities, we randomly selected 421 residents aged 65 and older with a diagnosis of dementia (up to a maximum number per facility), and we asked a direct care provider (identified by the administrator as the individual who provided the most hands-on care and knew the most about the resident's care, health, mood, and daily activities) to provide information about the resident as well as about his or her own attitudes, stress, and satisfaction. Each facility's administrator provided information regarding facility characteristics. The project was approved by the Institutional Review Boards of the Universities of North Carolina and Maryland, and data collection was conducted on site between September 2001 and February 2003.

Measures

We used three measures to collect data regarding attitudes, stress, and satisfaction.

Approaches to Dementia.—This measure (Lintern, Woods, & Phair, 2000) includes 19 attitudinal items, each scored from 1 (*strongly disagree*) to 5 (*strongly agree*). They are summed to form a total score (range 19–95) as well as a hope subscore (8 items, range 8–40) and a person-centered subscore (11 items, range 11–55). Higher scores indicate more positive attitudes. Example items indicative of hope (reverse scored) include "people with dementia are very much like children" and "it is important not to become too attached to residents." Items related to person-centered care include "it is important for people with dementia to be given as much choice as possible in their daily lives" and "people with dementia need to feel respected, just like anybody else."

Work Stress Inventory.—This measure (Schaefer & Moos, 1993) is a modification of the original measure and is derived by averaging the frequency of 45 stressors, each scored 1 (*never–not at all*) to 5 (*often–very well*). Higher scores indicate more stress, and subscales can be created for each of six domains: stress related to events, resident care, relations with coworkers, relations with supervisors, workload and scheduling, and physical design. Example items (one for each domain) ask about the past 30 days, and include the following: "how often have you had to do tasks for which you have little or no training?"; "how often have you cared for a resident who was uncooperative, angry, or complaining?"; "how often have you not gotten help from your coworkers when you needed it?"; "how often have you been uncertain about whether your supervisors think you are doing a good job?"; "how often have you had to work with staff who are inexperienced and poorly trained?"; and "would you describe your workplace as not having a place to get away from residents?"

Staff Experience Working With Demented Residents.—This measure (Åstrom, Nilsson, Norberg, Sandman, & Winblad, 1991) includes 21 items assessing satisfaction, each scored from 0 (*not at all*) to 4 (*extremely*) and summed to create a total score ranging from 0 to 84. Higher scores indicate more satisfaction, and subscales can be created for each of six domains: (satisfaction with) feedback, the care organization, one's own expectations, patient contact, expectations of others, and the environment. Example items (one for each domain) ask to what extent the following occur: "you experience contact with confused residents as stimulating"; "work flows well between day staff and night staff"; "relatives of demented residents respond to your expectations of them"; "you can be helpful and see to the needs of residents with dementia"; "you can respond to the expectation of your coworkers" and "your workplace is ideal for the care of demented residents."

Direct care providers also provided demographic information about themselves and reported on how well trained they considered themselves to be to assess and treat behavioral symptoms, depression, pain, activity involvement, mobility, and food and fluid intake (see related reports in this issue). Scores range from 0 (feels *not at all* or *a little* trained in all areas) to 21 (feels *extremely well trained* in all areas). Finally, facility administrators reported on facility size, age, profit status, whether it provided special care for residents with dementia, and resident case-mix.

Analyses

We computed simple descriptive statistics (means, standard deviations, and percentages) for facility and care provider demographic characteristics, as well as for care provider attitudes, work stress, and satisfaction. To develop the total and subscale scores on the measures of Approaches to Dementia, Work Stress Inventory, and Staff Experience Working With Demented Residents, we created summary scores if at least 75% of the component items were non-missing, with the scores rescaled to maintain the same range. We examined internal consistency by computing Cronbach's coefficient alpha for the total scores as well as for each subscale, basing it only on respondents with no missing items for each measure or subscore.

To estimate associations among attitudes, work stress, and satisfaction, we computed Pearson correlation coefficients for both total scores and subscales. We tested the statistical significance of these associations by using the general linear model with correlated errors (Diggle, Heagerty, Liang, & Zeger, 2002), specifying a compound symmetrical correlation structure within facilities. Using linear models, we tested bivariate associations between facility and care provider characteristics and each of the measures of attitudes, work stress, and satisfaction, with attitudes, stress, and satisfaction as the dependent variables and facility and care provider characteristics as the independent variables; again, we specified a compound symmetrical correlation structure for care providers within facilities. (Because we estimated a separate model for each association in the bivariate analyses, we conducted multiple statistical tests for each dependent variable; hence, interpretations of results are focused on characteristics associated with more than one measure.) Finally, we estimated the independent associations of the care provider and facility characteristics with attitudes, stress, and satisfaction, each in a single regression model that included all the facility and care provider characteristics (as well as attitudes, stress, and satisfaction, except when it was the dependent variable).

Table 1. Facilities and Direct Care Providers of the Dementia Care Study

Variable	N (%) or M (SD)
Facilities	
Type	
Nursing home	10 (24.4%)
RC/AL	
< 16 beds	10 (24.4%)
Traditional	11 (26.8%)
New-model	10 (24.4%)
Bedsize	67.0 (51.8)
Facility age	20.5 (21.6)
For profit	30 (73.2%)
Special care unit or facility	22 (53.7%)
Resident case-mix[a]	
Age, % 85 and older	41.9 (22.0)
Gender, % male	21.9 (14.4)
Race, % non-White	7.2 (12.6)
% Hispanic	0.8 (3.3)
% Medicaid	27.2 (30.5)
% bedfast	2.2 (4.3)
% chairfast	30.7 (24.3)
% dementia diagnosis	53.2 (23.7)
Direct care providers	
Gender, male	10 (6.5%)
Age	39.9 (12.4)
Education, some college	59 (38.8%)
Race	
Black	86 (55.8%)
White	56 (36.4%)
Other	12 (7.8%)
Hispanic	11 (7.2%)
Experience, time in present job	
< 6 months	11 (7.2%)
6–11 months	21 (13.7%)
1–2 years	25 (16.3%)
≥ 2 years	96 (62.7%)
Experience, with dementia residents	
< 1 year	14 (9.2%)
1–2 years	15 (9.8%)
≥ 2 years	124 (81.0%)
Perception of assessment training[b]	15.8 (3.7)
Perception of treatment training[b]	15.0 (3.9)

Notes: RC/AL = residential care/assisted living. For facilities, $N = 41$. The 4 facilities providing no staff data were all RC/AL with < 16 beds; 3 had only administrators or supervisors, and 1 had only one provider who did not complete the staff interview. Due to missing data for direct care providers, $N = 151–154$.

[a]Facility administrators reported case-mix for their facilities. Statistics reported are the M (SD) for these estimates.

[b]Perception of training is a summary score of adequacy of training to assess and treat behavioral symptoms, depression, pain, activity involvement, mobility, and food and fluid intake. Scores can range from 0 (feels *not at all* or *a little* trained in all areas) to 21 (feels *extremely well trained* in all areas); actual scores range from 3 to 21.

Results

A total of 154 direct care providers from 41 facilities provided data for these analyses (4 small facilities were not represented). In total, 64 direct care providers (42%) worked in RC/AL facilities, and 90 (58%) worked in nursing homes; further, 11 were administrators (in RC/AL facilities with <16 beds), 1 was a registered nurse, 1 was a licensed nurse, 136 worked at the level of a certified nursing assistant with no additional credentials, and the status of 5 is unknown. As shown on Table 1, the facilities in which these workers were employed were equally distributed by long-term care setting (i.e., approximately one fourth from each of the RC/AL facility types and nursing homes). They tended to be for profit (73%) and one half (54%) had a unit or facility that specialized in the care of residents with dementia. Slightly more than one half of the residents had dementia (53%); fewer were chairfast (31%) or on Medicaid (27%).

The care providers were primarily female (94%) and averaged 40 years of age (range 16–65). Slightly more than one half of the providers were Black (56%) and had been working in their job for 2 or more years (63%). The majority (81%) had been working with residents with dementia for 2 or more years. Finally, in an index of perceived competence of training, scores averaged 15 to 16 out of a possible 21, indicating high levels of perceived preparation for care in key domains.

Table 2 provides the descriptive statistics for the measures of attitudes, stress, and satisfaction, overall and by their respective domains, as reported by the 154 respondents. Attitudes and satisfaction were skewed toward the positive (mean of 70.7 out of a possible 95 and 62.3 out of a possible 84, respectively) and stress was skewed toward the negative (i.e., low stress; mean of 1.8 out of a possible 5). Scores aggregated on a facility level (not shown) were quite similar, averaging 71.0 $(SD = 4.7)$ for attitudes, 62.7 $(SD = 6.6)$ for satisfaction, and 1.8 $(SD = 0.4)$ for stress. Considering scores within each domain, we found that positive attitudes were most evident in the person-centered subscale (compared with the hope subscale); stress was highest in the caring for residents subscale; and satisfaction was highest in the patient contact subscale.

Correlations between the three measures (not shown) were −.03 (attitudes and stress), .21 (attitudes and satisfaction; $p < .01$), and −.24 (satisfaction and stress; $p < .01$). The strongest correlations between subscales and total scores were between person-centered care and satisfaction ($r = .28$, $p < .01$) and between stress with coworkers, supervisors, workload, and physical design, and satisfaction ($r = −.20$ to $−.27$; $p < .01$). The strongest correlations between subscales were between the attitude of person-centered care and satisfaction (with feedback and patient contact); and between satisfaction (with the organization and own expectations) and stress (related to coworkers and workload), all six of which ranged from $\pm.30$ to $\pm.45$ ($p < .001$).

Table 3 displays the relationship of the facility and care provider characteristics to subscales and total scores of attitudes, stress, and satisfaction, adjusted for facility-level clustering. Given the number of

Table 2. Descriptive Statistics of Attitudes About Dementia, Work Stress, and Satisfaction

Variable	M (SD)	Minimum	Maximum	Internal Consistency No. of Items	Cronbach's α
Attitudes about dementia					
Hope (theoretical range, 8–40)	24.1 (4.3)	10.0	36.0	8	.65
Person-centered care (11–55)	46.5 (3.8)	37.0	55.0	11	.75
Total (19–95)	70.7 (6.4)	49.0	88.0	19	.75
Work stress					
Work events (1–5)	2.0 (0.7)	1.0	4.0	7	.71
Caring for residents (1–5)	2.7 (0.9)	1.0	5.0	4	.68
Relationships with coworkers (1–5)	1.6 (0.6)	1.0	3.4	9	.85
Relationships with supervisors (1–5)	1.5 (0.7)	1.0	4.4	7	.90
Workload and scheduling (1–5)	1.8 (0.7)	1.0	4.1	8	.81
Physical design (1–5)	1.7 (0.8)	1.0	4.3	10	.86
Total (1–5)	1.8 (0.5)	1.0	3.8	45	.93
Staff satisfaction					
Experience of feedback at work (0–24)	17.9 (3.8)	8.0	24.0	6	.76
Care organization (0–12)	8.7 (2.2)	2.0	12.0	3	.65
Satisfaction of own expectations (0–12)	8.7 (2.1)	3.0	12.0	3	.41
Satisfaction with patient contact (0–12)	10.3 (1.5)	6.0	12.0	3	.58
Satisfaction with expectations of others (0–12)	7.7 (2.0)	0.0	12.0	3	.47
Satisfaction with environment (0–12)	9.1 (2.1)	3.0	12.0	3	.65
Total (0–84)	62.3 (9.9)	34.0	80.0	21	.87

Notes: For the table, $N = 154$. Table data are based on an average (SD) of 3.8 (2.7) staff in each facility.

comparisons that have been made, we find it advisable to focus on those that demonstrate consistency and are significant across variables. With that caveat in mind, it is first apparent that no facility or care provider characteristic related to all three outcomes of interest (attitudes, stress, and satisfaction); at best, variables related to two of the domains under study. Focusing first on facility characteristics, we found that only two variables were significantly associated with the summary measures: older facility age related to less optimal attitudes (the score for facilities older than 10 years was $M = 69.2$, $SD = 3.7$, compared with 73.2, $SD = 5.7$ for younger facilities; $p < .01$), and having a special care unit related to more stress ($M = 37.5$, $SD = 14.1$, vs 29.0, $SD = 17.2$; $p < .05$). None of the domains differed by the type of facility in which the staff worked (RC/AL or nursing home), and only a few resident characteristics were related to hope and some components of satisfaction, but not to work stress.

Care provider characteristics that were consistently associated with the variables under study include worker age, time in job, and perceived adequacy of training. Older workers consistently reported less stress: For those 45 years of age and older, the mean for the overall scale was 28.0 ($SD = 19.5$), compared with 34.0 ($SD = 22.9$) for those 35–44 and 45.2 ($SD = 26.3$) for those younger than 35 ($p < .01$ for both). Older workers also reported more satisfaction, although less consistently so (i.e., three of six subscales were significant). Staff who had been working for between 6 months and 2 years reported more stress (ranging 43.3–46.6, $SD = 28.5$, 23.8) than those working for more than 2 years ($M = 31.7$, $SD = 21.8$); however, those working for between 1 and 2 years reported more hope and person-centered attitudes ($M = 73.8$, $SD = 5.6$) than those working for a longer period of time ($M = 69.5$, $SD = 6.2$; $p < .01$). Additional analyses showed that staff who have been working for more than 2 years tended to be working in older facilities (i.e., facility age, $M = 29.9$ years vs 19.3–21.4 years for other staff age groups). Further, staff who feel they are better trained to assess and treat common sequelae of dementia were more likely to embrace a person-centered attitude ($r = .26$ and .29, $p < .002$, respectively) and to be more satisfied ($r = .58$ and .56, $p < .0001$, respectively). Finally, Black and other minority staff (who were more likely to be in their jobs for more than 2 years; data not shown) were less likely than Whites to report person-centered care ($M = 46.1$, $SD = 3.7$, and $M = 44.6$, $SD = 2.2$, respectively, vs $M = 47.6$, $SD = 4.0$; $p < .05$) but more likely to be satisfied with the environment ($M = 9.4$, $SD = 2.1$ and $M = 9.9$, $SD = 1.7$, respectively, vs $M = 8.5$, $SD = 2.0$; $p < .05$).

After adjusting for all facility and caregiver characteristics (see Table 4), hopeful or person-centered attitudes were more often espoused by workers with higher education ($p < .05$) and those working between 1 and 2 years (vs a longer period of time; $p < .10$); they were less often reported by those who are not Black (vs those who are White; $p < .01$). Stress was more often reported by men, younger workers, and those working between 1 and 2 years (vs a longer period of time; $p < .05$), but less often reported by workers in RC/AL facilities with <16

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Table 3. Facility and Staff Characteristics Related to Attitudes About Dementia, Work Stress, and Satisfaction

Characteristis	Attitudes About Dementia			Work Stress									Satisfaction				
	Hope	Person-Centered Care	Total	Events	Resident Care	Co-workers	Super-visors	Work-load	Physical Design	Total	Feed-back	Care Org	Own Expectations	Patient Contact	Others' Expectations	Environment	Total
Facility																	
Type of facility																	
RC/AL																	
< 16 beds																	
Traditional																	
New-model									−*						−**		
Nursing home (reference)																	
Facility age	−*	−**	−***								−*			−***			
For profit		+*	+*		+*												
Special care unit					+**			+**		+**		−**			−**		−*
Resident case-mix																	
Age 85+																	
Non-White	−**	−*															
Male	−**																
Chairfast	−*												+*		+**	+*	
Bedfast															+***		
Medicaid															+*		
Dementia diagnosis																	
Care provider																	
Male gender	−*		−*														
Age				+**		−***	−**		−**	−***	+*	+**		+**	−***		
Education, some college		+*															
Race																	
Other	−*	−**	−**									+*			+*	+**	
Black		−**	−**	−**		+**	+*	+*								+**	
White (reference)																	
Time in present job																	
< 6 months																	
6–11 months				+**		+**	+*	+**		+*			+*				
1–2 years	+**	+**	+***	+*			+***	+***		+***		−*	−*			−*	
> 2 years (reference)																	
Training; assessment	+***	+***	+***								+***	+***		+***	+***	+***	+***
Training; treatment	+***	+***	+*								+***	+***		+***	+***	+***	+***

	Regression Coefficient (SE)					
	Attitudes About Dementia		Work Stress		Satisfaction	
Characteristics	Unadjusted	Adjusted	Unadjusted	Adjusted	Unadjusted	Adjusted
Facility						
Type of facility						
RC/AL						
< 16 beds	0.87 (2.00)	−1.10 (4.01)	−0.13 (0.18)	−0.68 (0.33)[†]	0.03 (3.20)	1.57 (4.92)
Traditional	1.03 (1.56)	−1.16 (3.66)	−0.11 (0.14)	−0.19 (0.31)	1.38 (2.53)	6.85 (4.42)
New-model	1.86 (1.55)	−0.18 (3.33)	−0.11 (0.14)	−0.23 (0.28)	0.00 (2.52)	1.34 (4.04)
Nursing home (reference)	—	—	—	—	—	—
Facility size (per 10 beds)	−0.05 (0.12)	0.13 (0.22)	−0.00 (0.01)	0.01 (0.02)	−0.11 (0.19)	−0.29 (0.25)
Facility age (per 10 years)	−0.59 (0.20)**	0.02 (0.41)	0.00 (0.02)	0.04 (0.03)	−0.59 (0.36)	−0.81 (0.48)
For profit	2.08 (1.23)[†]	−0.19 (2.61)	0.15 (0.11)	0.30 (0.22)	−0.25 (2.01)	−3.26 (3.16)
Special care unit	0.53 (1.22)	−1.63 (2.12)	0.21 (0.10)*	−0.09 (0.18)	−3.50 (1.81)[†]	2.50 (2.56)
Resident case-mix (per 10%)						
Age 85+	−0.30 (0.29)	−0.34 (0.42)	0.00 (0.03)	0.02 (0.04)	0.18 (0.45)	−0.23 (0.51)
Non-White	−0.69 (0.39)[†]	−1.05 (0.72)	−0.02 (0.03)	−0.03 (0.06)	0.29 (0.57)	1.41 (0.86)
Male	−0.57 (0.53)	−0.12 (0.63)	−0.02 (0.01)	−0.02 (0.05)	0.47 (0.76)	0.10 (0.79)
Chairfast	−0.39 (0.24)	−0.50 (0.44)	−0.00 (0.02)	−0.07 (0.04)[†]	0.46 (0.34)	0.25 (0.54)
Bedfast	0.34 (1.57)	2.52 (2.43)	0.15 (0.12)	0.15 (0.21)	1.33 (2.19)	−0.42 (3.00)
Medicaid	−0.18 (0.19)	0.03 (0.35)	0.01 (0.02)	−0.00 (0.03)	−0.00 (0.28)	0.39 (0.43)
Dementia diagnosis	0.13 (0.29)	−0.05 (0.45)	0.01 (0.02)	0.03 (0.04)	0.41 (0.41)	−0.04 (0.54)
Care provider						
Male gender	−4.10 (2.07)[†]	−3.13 (2.34)	0.20 (0.17)	0.41 (0.19)*	2.69 (3.27)	0.89 (3.04)
Age	−0.02 (0.04)	−0.04 (0.06)	−0.01 (0.00)***	−0.01 (0.00)*	0.10 (0.07)	0.06 (0.07)
Education, some college	1.75 (1.05)[†]	2.75 (1.24)*	−0.05 (0.09)	−0.11 (0.10)	−0.71 (1.66)	−1.03 (1.63)
Race						
Other	−5.23 (1.98)*	−4.64 (2.38)[†]	−0.00 (0.17)	0.13 (0.20)	2.19 (3.21)	6.39 (3.03)*
Black	−2.58 (1.09)*	−1.82 (1.46)	−0.11 (0.10)	−0.10 (0.12)	1.32 (1.83)	1.20 (1.84)
White (reference)	—	—	—	—	—	—
Time in present job						
< 6 months	0.26 (1.98)	−1.16 (2.23)	0.02 (0.17)	−0.01 (0.18)	1.15 (3.16)	0.92 (2.87)
6–11 months	2.21 (1.50)	1.54 (1.76)	0.24 (0.12)[†]	0.14 (0.15)	−0.88 (2.39)	−0.27 (2.28)
1–2 years	4.09 (1.38)**	3.01 (1.64)[†]	0.33 (0.11)**	0.36 (0.13)*	−2.19 (2.20)	−1.41 (2.14)
> 2 years (reference)	—	—	—	—	—	—
Training: assessment	0.40 (0.13)**	0.26 (0.23)	−0.01 (0.01)	0.02 (0.02)	1.53 (0.18)***	1.09 (0.29)***
Training: treatment	0.30 (0.13)*	0.03 (0.21)	−0.02 (0.01)	0.00 (0.02)	1.43 (0.17)***	0.56 (0.26)*
Approaches to dementia	NA	NA	−0.01 (0.01)	−0.01 (0.01)	0.32 (0.12)*	0.18 (0.12)
Work stress	−0.77 (0.97)	−1.65 (1.15)	NA	NA	−4.42 (1.46)**	−2.45 (1.49)
Satisfaction	0.13 (0.05)*	0.10 (0.07)	−0.01 (0.00)**	−0.01 (0.01)	NA	NA

Notes: RC/AL = residential care/assisted living; NA = not applicable. Table data were adjusted for the facility and care provider characteristics shown. Regressions coefficients and standards errors were based on a general linear model with correlated errors, specifying a compound symmetrical correlation structure within facilities.
*$p < .05$; **$p < .01$, ***$p < .001$; [†]$p < .10$.

beds than by workers in nursing homes. Finally, satisfaction was higher among workers who are not Black (vs those who are White; $p < .05$), and those with more training in assessment ($p < .001$) and treatment ($p < .05$). Also of interest is that, although the results were not significant, workers in nursing homes reported the least favorable attitudes regarding dementia in unadjusted analyses, but the most favorable attitudes in adjusted analyses.

Discussion

In this article, using three relatively new measures that evaluate characteristics relevant to the provision of care for residents with dementia, we present the perspectives of 154 direct care providers surveyed from a range of long-term care facilities. In doing so, we focus attention on a neglected component of long-term care—frontline staff—and identify areas of practice that might benefit from attention. Our study also benefits the academic community by making more accessible three measures that are not commonly cited in the literature and that have adequate psychometric properties, which justifies their further use.

Adjusted analyses indicate varied associations with aggregate measures of attitudes, stress, and satisfaction. Of note, no facility characteristic

reached a significance level of $p < .05$. However, compared with workers in nursing homes, those in RC/AL facilities with <16 beds reported less stress ($p < .10$). This finding, coupled with the recognized structural merits of smaller facilities (e.g., providing a more homelike and familial environment) and beneficial resident outcomes (e.g., less functional and social decline over 1 year), recognizes yet another advantage of this supportive environment (Morgan, Gruber-Baldini, Eckert, & Zimmerman, 2004; Zimmerman, Sloane, Eckert, et al., 2005). Stress was also more often reported by male workers, younger workers, and those working for 1 to 2 years (vs longer); certainly, providing targeted support to such individuals seems warranted, especially as they have already demonstrated a level of job commitment. On a related matter, those individuals who have worked for 1 to 2 years were more likely to espouse hopeful or person-centered attitudes than those who have worked longer. Thus, attending to the welfare and ongoing training of these workers may lessen a tendency to become jaded over time or seek job opportunities elsewhere. More educated workers were also more likely to report dementia-sensitive attitudes, but, compared with White workers, those who were not Black (e.g., were Asian) were less likely to report such attitudes. Ironically, they were also more satisfied than White workers (as were workers who had more training). As the long-term care workforce is increasingly one of racial and ethnic diversity, these findings suggest that special consideration may be needed to ensure culturally sensitive care provision. Finally, of note is the shift in the direction of the relationship between facility type (RC/AL) and attitudes toward dementia, when relationships are adjusted for facility and care provider characteristics; this shift suggests that environmental and personal characteristics are likely to exert a strong influence on staff attitudes.

While adjusted analyses elucidate the independent contribution of facility and care provider characteristics to the outcomes under study, bivariate comparisons are useful because the relationship among characteristics and attitudes, stress, and satisfaction are rarely "adjusted" in the real world. In this regard, one of the most notable findings is that attitudes toward dementia care (and especially person-centered care) are related to worker satisfaction. To our knowledge, this study is the first to empirically assess correlates of person-centered care—the individualized mode of care thought to be the true intent of the quality-improvement nursing home reforms embodied in the Omnibus Budget Reconciliation Act of 1987 (Rader, 1995). The items reflective of this mode of care address the need to provide stimulating and enjoyable activities, choice, empathy, understanding and reassurance, respect, and care for psychological needs; to see residents as having abilities and reasons for their behavior; and to enjoy being with residents and believe that what is said to a person with dementia actually matters. Individualized care has been touted as important for the well-being of residents with dementia, but, until now, nothing has been documented about its relation to the well-being of the staff. To care for staff means to prepare them sufficiently (Kitwood, 1997), and a person-centered perspective may relate to staff satisfaction because it indicates better preparation for the challenging task of providing dementia care.

A person-centered attitude to care is more often reported by staff working in newer facilities and by those who feel better trained. Given the relative recency of the evolution of the philosophy of person-centered care, we find it highly plausible that its lower prevalence in older facilities represents an entrenchment of the more traditional medical model of care. Therefore, considering that a "facility culture" of dementia care can evolve over time (Mead, Eckert, Zimmerman, & Schumacher, 2005, this issue), administrators may be well advised to incorporate person-centered training into their list of priorities. They may want to consider using an instrument similar to the Approaches to Dementia measure to determine to what degree individual staff members espouse a dementia-sensitive attitude, and then develop and implement training curricula to bolster these attitudes. Although "goodness" and "kindness" may to some extent be innate qualities, sensitivity can be mentored and learned when such expectations are set (Fazio, Seman, & Stansell, 1999).

This study also finds that workers who perceive themselves to be better trained in dementia care are more likely to espouse person-centered care and report more satisfaction (the latter finding was significant in adjusted analyses, as well). Given the cross-sectional nature of this study, it is not clear whether training results in satisfaction or whether those who are more satisfied perceive themselves to be better trained. Similarly, it is possible that a person-centered attitude provides a necessary framework for perceptions of competence or that competence encourages a person-centered attitude. Nonetheless, these results suggest that the benefits of training extend beyond those afforded to residents, by allowing a worker to feel assured while conducting his or her tasks (Kitwood, 1997). Other studies also have found that staff training contributes to job satisfaction, motivation, and commitment (Gurnik & Hollis-Sawyer, 2003; Landi et al., 1999; Mackenzie & Peragine, 2003). In one intervention, for example, an 80-hr training session on providing care to people with dementia resulted in greater knowledge of Alzheimer's disease, job satisfaction, and satisfaction with job preparation (Mass, Buckwalter, Swanson, & Mobily, 1994).

On a less positive note, worker stress is higher in facilities with specialized dementia units. Other published studies of the relationship between specialized dementia units and staff stress have yielded

mixed results, with controlled studies suggesting that stress is not related to specialized dementia status per se but rather to factors such as dementia severity, staff-to-resident ratios, and staff training (U.S. Congress, 1992; also see McCarty & Drebing, 2002). Thus, one possible explanation for the detected relationship is that specialized settings provide care for a more impaired population, a hypothesis that is supported in this study by the finding that individuals with severe or very severe dementia were more prevalent in facilities with a special care unit (76% vs 52%, $p = .003$). Further, participants in facilities with special care units reported significantly more behavioral symptoms and slightly more impairment in activities of daily living (not significant). However, the fact that facility type and resident case-mix are not related to any of the variables under study argues against this hypothesis. Instead, it may be helpful to consider some of the items embedded in the two stress subscales that are significant (resident care and workload and scheduling), and the two subscales of satisfaction that are significant (satisfaction with the care organization and environment). These imply that specialized unit workers face a cluster of stressful challenges, including residents who are unappreciative or uncooperative, families who complain or need emotional support, understaffing, inexperienced coworkers, dissatisfaction related to work flow, and unmet expectations. Thus, facilities that have special care units (in this analyses, 45% of those in RC/AL and 80% of those in nursing homes) may attract a different demographic of clientele, suffer organizational challenges not evidenced in other facilities, and perhaps establish expectations that are difficult to meet. Considering that the majority of long-term care for residents with dementia is not provided in special care units (e.g., in RC/AL, 68% to 89% of residents who have moderate or severe dementia do not reside in special care facilities or units; see Sloane, Zimmerman, & Ory, 2001), and lacking data demonstrating the benefits of special care (Phillips et al., 1997), we believe it behooves administrators to reconsider the structure and goals of specialized units and to address deficits in the organization of that care. At minimum, facilities might benefit from administrative mechanisms to reduce stress and provide staff support (Gilster & McCracken, 1995).

As with all such work, limitations to this study must be acknowledged. Because facilities had to have a minimum number of residents with dementia to be eligible for study (i.e., 2 in facilities with < 16 beds and 13 in larger facilities), more facilities in this sample had special care units (54%) than is typical in RC/AL, where the actual range is from 8% to 25% (Sloane et al., 2001). However, this oversampling allowed for a more robust examination of the relationship of special care units to outcomes. In addition, this study is limited to workers in 41 facilities, and the data are self-report and may not be borne out in reality. Whereas attitudes, stress, and satisfaction may well best be self-report, assessing approaches to care is certainly best witnessed, but efforts do so are in their infancy (see Zimmerman, Sloane, Williams, et al., 2005, this issue, for new work in this area). Nonetheless, despite these limitations, understanding the correlates of worker attitudes and well-being offers an opportunity to improve not only the situation of the workers but also that of the residents for whom they care.

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Factors Associated With Nursing Assistant Quality-of-Life Ratings for Residents With Dementia in Long-Term Care Facilities

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Purpose: We identify resident, nursing assistant, and facility factors associated with nursing assistant quality-of-life ratings for residents with dementia in long-term care. **Design and Methods:** We used a cross-sectional survey of 143 nursing assistants providing care to 335 residents in 38 residential care/assisted living (RC/AL) facilities and nursing homes in four states. We assessed resident quality of life by using the Quality of Life–Alzheimer's Disease Scale (QOL-AD). **Results:** Scores on the quality-of-life scale were most strongly associated with resident clinical conditions, including severity of cognitive and functional impairments, depression, and behavioral symptoms of dementia. There was also an independent positive association between nursing assistants' ratings of resident quality of life and their own attitudes regarding dementia-person-centered care as well as training. However, the results of hierarchical linear modeling suggest that some sources of nursing assistant variability in quality-of-life ratings remain unidentified. **Implications:** Quality-of-life ratings by nursing assistants may be influenced by their attitudes about dementia and their confidence in addressing residents' fundamental care needs.

Key Words: Assisted living, Nursing home, Training, Attitudes, Care provider

Ensuring a good quality of life for residents in long-term care represents both an important goal and a difficult challenge (Kane, R. A., 2001). Many factors contribute to a resident's quality of life, including the organizational culture within the facility, the staff's quality of care, and the residents' values, priorities, and perceptions of their functional and cognitive capabilities (Beck, Ortigara, Mercer, & Shue, 1999). As quality of life has become a goal more frequently cited by residents, families, and health care professionals, there have been increasing efforts to conceptualize and accurately measure it. Now, multiple generic and disease-specific quality-of-life measurement instruments have been developed, but the science of quality-of-life measurement remains in its infancy (Kane, R. L., 2001).

Ideally, individuals are in the best position to both define and rate their own quality of life. However, cognitive impairment may prevent residents with dementia from rating their quality of life. Currently, more than 50% of the individuals in nursing homes have dementia, as do 23% to 42% of the individuals in residential care/assisted living (RC/AL) facilities (Zimmerman et al., 2003). Because residents with dementia comprise an enlarging population within long-term care facilities, fostering their quality of life merits particular attention.

Lawton (1994) initially developed a conceptual framework of quality of life in dementia that includes the domains of psychological well-being, behavioral competence, care environment, and perceived quality

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of life. In long-term care facilities, nursing assistants have a critical role in promoting these quality-of-life domains because they deliver the majority of personal care. Because they are in this key position, the perceptions they have about residents are critically important, as their attitudes may well influence the manner in which they provide care. Unfortunately, a recent study of nurses and nurse aides found that the five most prevalent perceptions they held of individuals with dementia were negative: They saw them as being anxious, having little control over their behavior, being unpredictable, being lonely, and being frightened and vulnerable (Brodaty, Draper, & Low, 2003). Complicating this situation, nursing assistants receive minimal resident care training and potentially no dementia-specific education, and they themselves recognize the need for more training; in fact, these workers emphasize that training is important to their ability to provide quality care (Schirm, Albanese, Garland, Gipson, & Blackmon, 2000).

Given their lack of dementia-care training, nursing assistants may rate resident quality of life on the basis of negative biases developed from daily interactions with severely impaired individuals rather than from more balanced observations of residents' remaining capabilities. Thus, nursing assistants may perceive quality of life from their own perspectives instead of from resident-centered observations (Boettcher, Kemeny, DeShon, & Stevens, 2004). Although quality-of-life ratings are ideally based on resident preferences and characteristics, factors related to nursing assistants themselves or the facilities in which they work may become important determinants of how nursing assistants both rate quality of life and make decisions for residents with dementia (Corazzini, McConnell, Rapp, & Anderson, 2004). Our aim in this study is to assess the relationship between resident, nursing assistant, and facility-level characteristics and nursing assistant quality-of-life ratings of long-term care residents with dementia.

Methods

Participants

The individuals in this study were participants in the Dementia Care project of the Collaborative Studies of Long-Term Care (CS-LTC). A total of 421 residents with dementia were recruited from a stratified sample of 35 RC/AL facilities and 10 nursing homes in Florida, Maryland, New Jersey, and North Carolina. The RC/AL facilities ranged from converted family homes with fewer than 16 beds to large, purpose-built facilities. The commonality of all of these facilities is that they are licensed by states at a non-nursing-home level of care and provide room, board, 24-hr oversight, and assistance with daily activities. For each sampled resident, an interview was conducted with the direct care provider who provided hands-on care and was most familiar with the resident's health and care. The analyses presented here were restricted to the 335 residents who had their quality of life rated by one of 143 nursing assistants. Ninety-six percent of the nursing assistants were certified. There were no statistically significant differences between the 86 residents without a nursing assistant quality-of-life score and those with a score in terms of age, gender, or severity of cognitive impairment. Residents in nursing homes were more likely to have a quality-of-life rating by a nursing assistant than those in RC/AL facilities (90.5% vs 74.3%, $p = .03$). Further details about the sample and data-collection strategies are presented in the introduction to this issue.

Measures

The primary outcome measure was the nursing assistants' rating of resident quality of life, according to the Quality of Life–Alzheimer's Disease scale (QOL-AD; Logsdon, Gibbons, McCurry, & Teri, 2002). This instrument evaluates the following domains: physical condition, mood, interpersonal relationships, ability to participate in meaningful activities, and financial situation. The original instrument contains 13 items and was designed for community-based settings. A modified version more appropriate for long-term care changed the item "marriage relationship" to "relationships with people who work here," "ability to do chores" to "ability to keep busy," and "ability to handle money" to "ability to take care of self." In addition, 2 new items, "ability to live with others" and "ability to make choices in (one's) life," were added (Edelman, Fulton, Kuhn, & Chang, 2005, this issue). The modified QOL-AD includes 15 items, each of which is rated on a 4-point scale (1 = *poor* to 4 = *excellent*), with the total score ranging from 15 to 60. The internal consistency reliability of this measure was excellent ($\alpha = 0.88$) and the interrater reliability was 0.99 (intraclass coefficient, $n = 20$). Further, the care provider QOL-AD ratings were correlated with their quality-of-life scores by use of other established instruments: Ratings were positively correlated with both the positive affect scale ($r = .46$) and the activity scale ($r = .52$) of the Quality of Life in Dementia instrument (Albert et al., 1996), and there was also a strong positive correlation ($r = .68$) with the Alzheimer Disease-Related Quality of Life measure (Rabins, Kasper, Kleinman, Black, & Patrick, 2000). This and other information related to the QOL-AD is reported in this issue (Sloane et al., 2005).

We evaluated variables at three levels (facility, resident, and nursing assistant) for their relationship to nursing assistants' QOL-AD scores. At the facility level, these variables included facility type (RC/AL facility or nursing home) and profit–nonprofit status. At the resident level, in addition to demographic characteristics, we assessed cognitive status by using the Mini-Mental State Exam (MMSE; Folstein,

Folstein, & McHugh, 1975), or the Minimum Data Set Cognition Scale (MDS-COGS; Hartmaier, Sloane, Guess, & Koch, 1994) if an MMSE result was unavailable ($n = 48$). We assessed functional status by using the Minimum Data Set Activities of Daily Living Scale (MDS-ADL; Morris, Fries, & Morris, 1999), depression by using the Cornell Scale for Depression in Dementia (CSDD; Alexopoulos, Abrams, Young, & Shamoian, 1988), pain intensity with the Philadelphia Geriatric Center Pain Intensity Scale (PGC-PIS; Parmelee, Katz, & Lawton, 1991), and behavioral symptoms with the Cohen-Mansfield Agitation Inventory (CMAI; Cohen-Mansfield, 1986). The MDS-COGS, functional status, depression, pain, and behavioral ratings were all provided by a more senior staff member (such as a registered or licensed practical nurse) who supervised the nursing assistant.

We used three established instruments to evaluate nursing assistants' attitudes toward residents with dementia and their work experiences. The Approaches to Dementia instrument assesses attitudes toward caring for people with dementia, and it includes two subscales (Lintern, Woods, & Phair, 2000). Items in one subscale address a respondent's degree of hope for individuals with dementia, and questions in the other subscale assess the degree to which respondents endorse items related to ''person-centered care'' as opposed to considering that all residents with dementia have the same strengths and limitations. The Staff Experience Working with Demented Residents instrument contains six subscales that measure respondents' satisfaction with their work environment and experiences caring for residents with dementia (Åström, Nilsson, Norberg, Sandman, & Winblad, 1991). Finally, the Work Stress Inventory includes six subscales that assess work experiences during the past 30 days, including relationships with coworkers and satisfaction with work load and scheduling (Schaefer & Moos, 1993). Another article in this issue provides additional details about these three measures (Zimmerman et al., 2005).

Finally, using a series of questions developed for this study, we assessed nursing assistants' confidence in their training to both identify and help residents in multiple domains of dementia care (depression, behavioral symptoms, pain, eating, drinking, mobility, and activity involvement). For each of these areas, staff was asked to rate how well trained they felt both to identify problems affecting their residents (assessment) and to help with those problems (treatment). We scored responses on a 4-point scale and summed them across all areas to compute a training-assessment score and a training-treatment score. We summed these two indices to create an overall training score.

Statistical Analysis

To estimate bivariate associations between facility, resident, and nursing assistant characteristics and QOL-AD scores, we used Pearson correlation coefficients and means (standard errors) for continuous and categorical measures, respectively. We adjusted the standard errors of the means for resident clustering within nursing assistants and nursing assistants within facilities by using Taylor series expansion methods (Woodruff, 1971). We tested the statistical significance of these associations by using linear mixed models including random effects for facility and nursing assistants nested within facilities.

To examine whether the associations between facility and nursing assistant characteristics and QOL-AD scores were independent of resident characteristics, we estimated partial correlation coefficients and repeated the linear mixed models, adjusting for the resident covariates noted earlier: cognitive status, number of activities of daily living (ADL) disabilities, depressive symptoms, pain severity, and frequency of behavioral symptoms. We selected these covariates because they are likely to influence nursing assistants' perceptions and are often associated with quality-of-life ratings. Indeed, in this study the association of each covariate with the QOL-AD yielded a value of $p < .1$.

We excluded 70 residents from some analyses because data for at least one resident covariate were missing. Comparing residents with and without all covariate data, we found that there were no statistically significant differences in their mean QOL-AD scores (37.0 vs 38.4, $p = .57$), mean MMSE scores (8.3 vs 6.7, $p = 0.90$), gender (82% vs 74% female, $p = .39$), or whether they resided in a nursing home (36% vs 40%, $p = 0.51$) or for-profit facility (68% vs 76%, $p = 0.31$). However, residents with all covariate data available were younger than those with missing covariates (mean age 84.2 vs 86.3 years, $p = 0.02$).

We used a hierarchical linear model to estimate the extent to which variability in QOL-AD scores is explainable by factors related to the resident, to the nursing assistant, and to the facility. The use of a hierarchical model addresses statistical issues involving correlated multilevel data such as these, in which nursing assistants could be caring (and reporting the quality of life) for multiple residents, and study facilities could employ multiple nursing assistants. Our first step in this hierarchical model was to separate the total variability in QOL-AD scores into between-resident, between-nursing assistant, and between-facility components. We accomplished this by fitting a random intercepts model (no fixed effects) that provided estimates of variance and the standard error for each component. We then created a series of models in which resident, nursing assistant, and facility factors were added sequentially to identify significant effects on QOL-AD scores and to explore how the variance partitioning changes upon adding these factors to the regression. After each step, we assessed the change in between-resident, between-nursing assistant, and between-facility variation. If a variance component diminishes substantially after

Table 1. Mean Nursing Assistant Quality of Life–Alzheimer's Disease Score by Selected Resident Characteristics

Resident Characteristic	No. of Residents	No. of Nursing Assistants	Mean QOL-AD Score (SE)[a]	p[b]
Age				
< 80 years	75	54	37.36 (1.07)	.82
80–84 years	90	66	36.69 (0.88)	
85–89 years	86	63	38.06 (1.02)	
≥ 90 years	76	59	37.00 (0.83)	
Gender				
Male	67	52	37.45 (0.84)	.74
Female	268	133	37.22 (0.64)	
Race				
White	263	113	37.03 (0.67)	.53
Non-White	30	23	39.00 (1.69)	
ADL function (no. dependent)				
0–2	95	48	40.95 (0.94)	< .0001
3–5	92	59	38.04 (0.96)	
6–7	99	73	32.79 (0.79)	
Cognitive impairment[c]				
Mild	43	33	42.67 (1.14)	< .0001
Moderate	83	57	39.40 (0.85)	
Severe	86	65	37.21 (0.83)	
Very severe	115	79	34.02 (0.85)	
Cornell Depression Scale[d]				
< 7	214	99	37.64 (0.68)	.008
≥ 7	63	47	35.08 (1.11)	
Behavioral symptoms of dementia				
None	118	64	38.07 (0.78)	.019
At least weekly	159	91	36.30 (0.75)	
PGC-PIS[e]				
< 2	210	95	36.49 (0.66)	.080
≥ 2	55	37	38.78 (1.30)	

Notes: QOL-AD = quality of life–Alzheimer's disease; ADL = activity of daily living; PGC-PIS = Philadelphia Geriatric Center–Pain Intensity Scale. For residents, $N = 335$; for care providers, $N = 143$. An individual nursing assistant may provide a QOL-AD score for a resident in more than one row. Ns vary across measures because of missing data.

[a]Adjusted for clustering of residents within nursing assistants and nursing assistants within facility using Taylor series expansion models.

[b]Based on linear mixed models including random effects for facility and nursing assistants nested within facilities and the single fixed effect as shown.

[c]Assessment of cognitive impairment is based on Mini-Mental State Examination (MMSE) or Minimum Data Set–Cognition (MDS-COGS) scores. Cutpoints for mild, moderate, severe, and very severe, are ≥ 17, 10–16, 3–9, 0–2, respectively (MMSE); 0–1, 2–4, 5–6, and 7–10, respectively (MDS-COGS).

[d]A Cornell Depression Scale cutpoint of 7 suggested for minor depressive disorder (Alexopoulos et al., 1988).

[e]In this sample, a cutpoint of 2 corresponded to an average across the 6 items in the PGC-PIS instrument of "a little" pain or worse.

a set of characteristics is included in the model, we can conclude that such variations are in part the result of these characteristics.

We included individual variables that were associated with QOL-AD scores in the unadjusted analysis at $p ≤ .05$, with one exception. Although both frequency of residents' behavioral symptoms of dementia and number of depressive symptoms were significantly associated with nursing assistants'

QOL-AD ratings, these two variables were also strongly correlated ($r = .56, p < .001$). We included only frequency of behavioral symptoms in the final model because agitation and other behaviors are more likely to affect nursing assistant ratings of residents with dementia than less easily detected depressive symptoms. Despite not having significant associations with QOL-AD in the unadjusted analysis, we also included the measures related to nursing assistant age, training, approaches to dementia, and staff experience working with demented residents because of hypothesized clinical relevance.

Results

Table 1 presents resident demographic and clinical characteristics by their QOL-AD scores as rated by nursing assistants. A total of 143 nursing assistants rated 335 residents' quality of life. On average, each nursing assistant rated the quality of life of 2.3 residents (range 1–9). There was no association between nursing assistants' QOL-AD ratings and resident age, gender, or race. There was a statistically significant inverse relationship ($p < .001$) between QOL-AD scores and both resident functional and cognitive impairments. In addition, depression was associated with a lower QOL-AD rating ($p = .008$), as was the presence of at least one behavioral symptom per week ($p = .019$). Residents with pain scored marginally higher on the QOL-AD ($p = .08$).

Table 2 shows the crude and adjusted relationships between selected nursing assistant and facility characteristics and nursing assistants' QOL-AD ratings. In both the crude and adjusted analyses, there were no associations between nursing assistants' age, gender, or race and their QOL-AD ratings. There also were no statistically significant differences in QOL-AD scores based on certification status of nursing assistants and which shift they most commonly worked. (Comparisons may be limited by the small number of men and noncertified nursing assistants in this sample, however.) In the unadjusted analysis, residents received higher QOL-AD ratings from nursing assistants who had been in their current position for less than 1 year compared with those who had been in their position for more than 1 year. Residents in RC/AL facilities and for-profit facilities also received higher QOL-AD ratings from their nursing assistants than those in nursing homes and not-for-profit facilities. However, these differences did not persist after we adjusted for residents' clinical characteristics.

Table 3 presents the correlations between QOL-AD scores of nursing assistants and their responses on several instruments that measure their training, attitudes, and beliefs regarding individuals with dementia, and their work experiences. There were statistically significant positive correlations between

Table 2. Mean Nursing Assistant Quality of Life-Alzheimer's Disease Score by Selected Nursing Assistant and Facility Characteristics

Characteristic	No. of Residents	No. of Nursing Assistants	Mean QOL-AD Score (SE)[a]	*p* Unadjusted[b]	*p* Adjusted[b,c]
Nursing assistant					
Age					
< 40 years	136	61	35.76 (0.82)	.23	.77
≥ 40 years	125	47	38.33 (0.93)		
Gender					
Male	9	6	39.22 (4.27)	.09	.31
Female	256	105	36.89 (0.66)		
Race					
Black	121	53	36.38 (0.94)	.95	.90
White	126	48	37.53 (0.93)		
Other	18	10	36.94 (2.36)		
Certified as CNA					
No	6	3	40.50 (3.54)	.37	.24
Yes	259	108	36.88 (0.65)		
Most common work shift					
Day	216	91	36.60 (0.71)	.16	.16
Other	48	19	38.63 (1.69)		
Time in current position					
< 1 year	60	25	38.97 (1.60)	.02	.15
≥ 1 year	203	84	36.32 (0.69)		
Facility					
Facility type					
RC/AL	169	59	38.30 (0.75)	.02	.80
Nursing home	96	52	34.63 (1.04)		
Profit status					
Not for profit	85	39	34.62 (1.07)	.02	.14
For profit	180	72	38.07 (0.76)		

Notes: QOL-AD = quality of life–Alzheimer's disease; RC/AL = residential care/assisted living; CNA = certified nursing assistant. For residents, N = 265; for care providers, N = 111. Ns vary across measures because of missing data.

[a]Adjusted for clustering of residents within nursing assistants and nursing assistants within facility using Taylor series expansion methods.

[b]Based on linear mixed models including random effects for facility and nursing assistants nested within facilities, and either the single fixed effect shown (unadjusted analyses) or the fixed effect shown plus the covariates noted (adjusted analyses).

[c]Adjusted for residents' cognitive impairment, number of ADL disabilities, depressive symptoms, pain severity, and frequency of behavioral symptoms.

beliefs by nursing assistants that they were well trained and their QOL-AD ratings for residents (p = .03). In addition, there were positive albeit modest correlations between nursing assistants' attitudes about dementia, as measured by the Approaches to Dementia instrument, and their QOL-AD ratings after multivariate adjustment (p = .09). Although there was no association between the Approaches to Dementia Hope subscale and QOL-AD scores, we did observe a positive correlation between the Person-Centered subscale and QOL-AD scores (p = .006).

In unadjusted analyses, nursing assistants who reported more work stress provided statistically significantly lower QOL-AD scores than nursing assistants who reported less stress (p = .04). Two of the Work Stress Inventory's subscales also were significantly negatively correlated with QOL-AD scores: the Caring for Residents subscale, which assesses whether nursing assistants believed that they were appreciated by residents and families, and the Physical Design subscale, which evaluates nursing

assistants' satisfaction with the facility's physical environment. However, none of these correlations remained statistically significant after we adjusted for resident characteristics. Similarly, we found no statistically significant correlations between nursing assistants' experience and satisfaction working with demented residents and their QOL-AD ratings in either the unadjusted or adjusted analyses.

Table 4 shows the results of the hierarchical linear modeling to predict QOL-AD scores. The first model (no fixed effects) divides the total variability in QOL-AD scores (64.52 = 48.87 + 9.36 + 6.29) into between-resident, between-nursing assistant, and between-facility components prior to the inclusion of any fixed effects (independent variables). In this model, 76% (48.87/64.52) of the overall variability in QOL-AD scores is due to differences among residents, 14% (9.36/64.52) results from differences among nursing assistants, and 10% (6.29/64.52) is from differences among facilities. Thus, a large amount of variation in QOL-AD

Table 3. Correlations of Nursing Assistant Quality of Life–Alzheimer's Disease Score With Nursing Assistant Training, Approaches, Stress, and Experiences

Variable	Unadjusted		Adjusted[a]	
	Correlation	p	Correlation	p
Training, total				
(theoretical range 0–42)	.108	.07	.137	.03
Assessment (0–21)	.034	.26	.091	.08
Treatment (0–21)	.156	.03	.151	.03
Approaches to dementia,				
total (19–95)	.043	.33	.100	.09
Hope (8–40)	−.025	.92	−.017	.90
Person-centered				
care (11–55)	.100	.12	.188	.006
Work stress, total (6–30)	−.169	.04	−.053	.34
Caring for residents (1–5)	−.172	.02	−.117	.05
Relationships with				
coworkers (1–5)	−.135	.14	.022	.96
Relationships with				
supervisors (1–5)	−.081	.44	.017	.78
Work load and				
scheduling (1–5)	−.111	.10	−.037	.20
Physical design (1–5)	−.200	.02	−.120	.14
Work events (1–5)	−.065	.69	−.011	.97
Staff experience working				
with demented				
residents, total (0–84)	.130	.18	.100	.26
Experience feedback (0–24)	.114	.30	.057	.67
Care organization (0–12)	.167	.09	.101	.32
Satisfaction of own				
expectations (0–12)	.110	.17	.077	.25
Satisfaction with patient				
contact (0–12)	.103	.15	.085	.22
Satisfaction with others'				
expectations (0–12)	.000	.93	.067	.37
Satisfaction with work				
environment (0–12)	.091	.47	.087	.41

Notes: N ranges from 249 to 253 among the nursing assistant measures because of missing data; however, for each measure, the sample size is the same in the unadjusted and adjusted analyses. p values are based on linear mixed models including random effects for facility and nursing assistants nested within facilities, and either the single fixed effect shown (unadjusted analyses) or the fixed effect shown plus the covariates noted (adjusted analyses).

[a]Adjusted for residents' cognitive impairment, number of ADL disabilities, depressive symptoms, pain severity, and frequency of behavioral symptoms.

scores occurs at the resident level ($p < .001$), and small amounts of variation occur among nursing assistants ($p = .07$) and among facilities ($p = .07$).

Adding resident measures to the model decreased residual variability among QOL-AD scores; 31% [$1 − (33.65/48.87) \times 100\%$] of the variability in QOL-AD scores attributable to between-resident differences was explained by the resident-level characteristics used in this model. The model with resident factors reveals that higher cognitive impairment, more ADL disabilities, and more

frequent behavioral manifestations of dementia are significantly related to lower QOL-AD scores. For example, having one additional ADL impairment results in QOL-AD scores that are on average 1.13 points lower. Residents with very severe cognitive impairment had a QOL-AD score that on average was 5.63 points lower than that of residents with mild cognitive impairment. For each behavioral symptom observed, QOL-AD scores decreased by 0.45 points. Although the initial between-facility variance was small, more than one half of this variance was explained by resident characteristics.

The next model assessed nursing assistant characteristics adjusted for the resident characteristics in the model. The nursing assistant factors were age of the nursing assistants and their summary scores on the Training, Work Stress Inventory, Approaches to Dementia, and Staff Experience Working With Demented Residents instruments. The nursing assistant variance slightly decreased in comparison with the initial model. Only 3% [$(1 − (12.71/13.16)) \times 100\%$] of the variance was explained by the nursing assistant characteristics in the model. None of the nursing assistant characteristics included in the model were statistically significant. The facility variance increased slightly after we added nursing assistant variables from the model that adjusted only for resident characteristics. The estimates of the magnitude of the resident characteristics and the resident-level variance change little when we add nursing assistant and facility characteristics to the model.

The final model evaluated facility factors after adjustment for resident and nursing assistant characteristics. The nursing assistant variance increased slightly from the model that did not adjust for facility factors. The facility variance decreased slightly; 25% [$(1 − (2.78/3.70)) \times 100\%$] of the facility-level variance was explained by the facility factors in the model. With respect to the initial model that had no fixed effects, 56% [$1 − (2.78/6.28) \times 100\%$] of the variability in QOL-AD scores attributable to between-facility characteristics was explained, whereas virtually none of the between-nursing assistant QOL-AD score variability was explained by the measures included in the analysis. In this final model, only resident characteristics had a significant effect in explaining QOL-AD score variation; neither nursing assistant nor facility characteristics were statistically significant.

Discussion

This study increases understanding of how nursing assistants in long-term care perceive the quality of life of residents with dementia. What is most important is that the results demonstrate that nursing assistants' QOL-AD ratings are related to their own attitudes toward residents with dementia and by their own perceived competence to address residents' funda-

Table 4. Predictors of Nursing Assistant Estimates of Resident Quality of Life: Parameter Estimates From Hierarchical Linear Model for Nursing Assistant Quality of Life–Alzheimer's Disease Score

Measure	Model and Parameter Estimate (SE)[a]			
	No Fixed Effects	Plus Resident	Plus Resident and Nursing Assistant	Plus Resident, Nursing Assistant, and Facility
Intercept[b]		46.00 (1.30)***	38.46 (7.82)***	36.77 (7.87)***
Resident characteristics				
Cognitive impairment				
Mild (reference)		—	—	—
Moderate		−3.16 (1.40)*	−3.24 (1.41)*	−3.23 (1.41)*
Severe		−4.15 (1.46)**	−4.27 (1.46)**	−4.15 (1.46)**
Very severe		−5.63 (1.54)***	−5.72 (1.55)***	−5.59 (1.55)***
No. of ADL disabilities		−1.13 (0.21)***	−1.18 (0.21)***	−1.23 (0.22)***
No. of behavioral symptoms		−0.45 (0.19)*	−0.44 (0.20)*	−0.48 (0.20)*
Nursing assistant characteristics				
Age (years)			−0.02 (0.05)	0.01 (0.05)
Training score			0.19 (0.10)†	0.17 (0.10)†
Approaches to dementia[c]			0.10 (0.09)	0.09 (0.09)
Work stress[d]			−1.07 (1.09)	−1.48 (1.11)
Experience and satisfaction[e]			−0.04 (0.07)	−0.04 (0.07)
Facility characteristics				
Nursing home (vs RC/AL)				3.09 (1.76)†
For profit				3.05 (1.72)†
Variance components				
Resident	48.87 (5.51)***	33.65 (4.05)***	33.55 (4.04)***	33.31 (3.98)***
Nursing assistant	9.36 (6.06)†	13.16 (5.68)**	12.71 (6.00)*	13.20 (5.94)*
Facility	6.29 (4.27)†	2.33 (2.98)	3.70 (3.73)	2.78 (3.67)

Notes: ADL = activity of daily living; RC/AL = residential care–assisted living. For the table, $n = 252$.
[a]The parameter estimates reflect the incremental change in quality-of-life rating for each one-unit increase in the resident, nursing assistant, or facility characteristic of interest, adjusting for the other characteristics, or, for categorical measures, the change in quality-of-life rating for the given level compared to the reference group. For example, in the full model, quality-of-life rating decreases an average of 1.23 points for each additional ADL disability, while those with very severe cognitive impairment receive quality-of-life ratings an average of 5.59 points lower than those with mild impairment.
[b]The intercept is the overall mean quality-of-life rating, adjusted for the fixed covariates in a given model.
[c]Approaches to dementia: summary score range = 19–95.
[d]Work stress inventory: total score = average of 45 items, with each item scored 1–5.
[e]Staff experience working with demented residents: summary score range 0–84.
*$p < .05$; **$p \leq .01$; ***$p < .001$; †$p < .10$.

mental care needs. To our knowledge, this study is the first to examine and demonstrate associations between resident quality-of-life ratings and attitudes of nursing assistants regarding their training and person-centered care.

Providing person-centered care has been emphasized as important to the quality of care and life of residents with dementia (Kitwood, 1997). In this practice model, care providers form relationships with residents with dementia and they seek to understand and address their individual needs despite their functional and cognitive deficits (Touhy, 2004). The goals of person-centered care and quality-of-life perception are complementary, as each focuses on resident individuality and attempts to avoid generalizations about residents—generalizations that are often negative in nature.

he positive association between attitudes of nursing assistants regarding person-centered care and their resident QOL-AD scores may indicate that care providers who perceive residents with dementia as having the capacity to engage in relationships and

activities also will consider that their lives have quality. These care providers may be more likely to provide person-centered care, although this study did not examine care providers' actual treatment of residents. Alternatively, it is possible that those care providers who value the quality of life of residents with dementia will perceive them as individuals. Therefore, the directionality of this relationship is unclear.

In addition, nursing assistants with greater confidence in their training to assess and treat residents' personal care needs had higher resident QOL-AD ratings. Because training confidence may serve as a proxy for perceptions by care providers of their care quality, nursing assistants may believe that resident quality of life depends on the quality of their care. Further, it is possible that training regarding person-centered care principles will result in improved quality-of-life ratings. Person-centered care training would seek to minimize biases held by nursing assistants about dementia that affect their perceptions of resident quality of life. Thus, training

to address and treat care needs such as ADLs should monitor not only the competence of care providers but also their confidence. Once again, because directionality is uncertain, it should be considered that nursing assistants who value resident quality of life feel less overwhelmed by, and better able to address, resident quality-of-life needs. Either way, valuing quality of life appears likely to be beneficial to care provision, although the relationship between quality-of-life perceptions and care quality merits further study.

Although the attitudes of nursing assistants were related to their QOL-AD scores, resident clinical status was the most significant predictor of care provider QOL-AD ratings. As resident functional and cognitive impairments increased, QOL-AD scores progressively decreased. In bivariate analyses, the two characteristics associated with the lowest mean QOL-AD scores were dependence in six to seven ADLs and very severe cognitive impairment. In addition, residents with depression and behavioral symptoms received lower QOL-AD ratings from their care providers.

Prior studies of community-based residents with chronic illness and dementia have demonstrated that functional status and depression are strongly associated with both resident and family caregiver quality-of-life ratings (Logsdon et al., 2002; Patrick, Kinne, Engelberg, & Pearlman, 2000). In one of these studies, cognitive impairment severity was not correlated with QOL-AD scores among community-dwelling individuals (Logsdon et al.). Thus, as measured by the QOL-AD, it is possible that dementia may have a greater perceived impact on quality-of-life ratings in long-term care. That is, nursing assistants may be comparing multiple residents in their care when rating any single resident's quality of life. A family member's rating for a loved one is based on a long-term relationship with that individual, and therefore it may be attenuated by the slow trajectory of decline witnessed over time.

It is also important to note that QOL-AD scores from long-term care staff in this study were unbiased by residents' or nursing assistants' demographic characteristics, including age, gender, or race. However, the racial diversity among the residents was limited (8% were African American), which generally reflects the distribution of residents in RC/AL and nursing homes (Howard et al., 2002). Thus, the relationship of quality of life to residents' race is one that has yet to be sufficiently examined. Nonetheless, the results of this study suggest that nursing assistants focus on residents' clinical characteristics when they are assessing quality of life.

It should be recognized that a low quality-of-life rating may be appropriate and consistent with residents' own values. Low scores can provide an opportunity to reassess residents' care plans and ensure that their treatment decisions are consistent with resident preferences, are focused on areas important to quality of life, and are not unduly burdensome. In addition, decreases in quality-of-life perceptions may prompt a discussion of palliative care approaches with residents' families, and thus serve as an indicator of care needs, rather than as an outcome of care, as is often the case.

Although this study demonstrates significant associations between QOL-AD scores and both resident and care provider characteristics, another important finding is that a substantial portion of the QOL-AD score variability among residents with dementia was not explained by the characteristics included in the hierarchical linear model. Although most of the variability [$48.87/64.5 \times 100\% = 76\%$; see Table 4] in care provider QOL-AD scores results from differences among residents, only 30% of the variance was explained by covariates in the model. The unexplained QOL-AD variability may result, in part, from one or more unmeasured covariates, or measurement error for the covariates included in this study. Given the importance of understanding the factors associated with nursing assistant quality-of-life observations, future research should further examine the factors associated with variability in QOL-AD ratings. Researchers may identify unmeasured covariates in future studies by including measures of resident behavior other than behavioral symptoms, such as the degree of residents' physical contact and engagement (Bradford Dementia Group, 1997; Sloane et al., 1998). Refining the instruments used to assess care provider attitudes and training confidence may be another approach to reducing the variability in QOL-AD scores.

Research efforts to define and measure quality of life in residents with dementia remain in their early stages (Whitehouse, Patterson, & Sami, 2003). To our knowledge, this study is the first to assess how care providers rate the quality of life of long-term care residents with dementia. In this study we found that, although approximately one fourth of the variability of QOL-AD scores was attributed to variations among care providers or variations among facilities, the overall care provider and facility variation was mostly unexplained by the care provider and facility characteristics examined. In addition to identifying further care provider and resident factors associated with quality-of-life ratings, future studies may examine whether improving care provider person-centered attitudes and training results in improved resident quality-of-life ratings. Given that optimal quality of care is a fundamental goal for residents with dementia, the association between nursing assistant quality-of-life ratings and care quality also should be evaluated.

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Sociocultural Aspects of Transitions From Assisted Living for Residents With Dementia

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Purpose: Negotiating transitions and residential relocation are especially difficult for residents with dementia and their families. This article examined the decision-making process regarding retention or transfer of persons with dementia in assisted living facilities. **Design and Methods:** Using an ethnographic approach, this study observed residents and facility life, and interviewed residents, staff, and family members in three assisted living facilities. **Results:** Facility managers and administrators are pivotal figures in determining the timing of transitions and transitional care. Operating within the context of care requirements of dementia, they, the facility culture, and the family members' involvement in resident care mediate interpretations of and responses to change and decline, and ultimately influence decision making regarding retention or transfer. **Implications:** Transfer or retention may occur differently depending on whether managers are on- or off-site, the assisted living culture is dementia-friendly, and families are involved in care. Sensitizing assisted living managers and educating potential residents and family members to the importance of these factors may affect the eventual likelihood and timing of discharge.

Key Words: Transitional care, Culture, Leadership, Family

As "nonmedical" residential environments, assisted living facilities are not necessarily the final care setting for many residents as their needs change. Residents may transition from a "general" facility to a dementia-specific facility or unit, a nursing home, or a special care unit within a nursing home. They also may transition from the facility to an acute care hospital and to a rehabilitation facility and back to the facility. Obviously, the possible trajectories are multiple, varied, and individual.

Several earlier studies (Hawes, Rose, & Phillips, 1999; Kane & Wilson, 1993; Stocker & Silverstein, 1996) have investigated reasons for discharge of residents from assisted living facilities, based on administrator responses to cross-sectional inquiries (mailed surveys, interviews, and telephone surveys, respectively). Their findings indicate that needing more care than the facility could provide, specifically related to behavioral, medical, and functional problems, was the most frequently cited reason for discharge. In the most recent of these studies (Hawes et al.), more than 50% of assisted living facility administrators reported they would not retain residents with moderate to severe cognitive impairment, and 76% of the facilities cited behavioral problems as the most common reason for discharge.

In a study specific to discharge of residents with dementia from assisted living facilities to skilled nursing care, Aud (2000, 2002) used single ethnographic interviews to examine resident behaviors that contributed to the decision to discharge. Aud found that the interaction of behavior with environment, rather than any isolated behavior, most strongly influenced staff decision making. Also, enforcement of a state regulation related to fire safety, which required mandatory discharge of residents who failed to demonstrate successfully their ability to independently navigate a predefined "path to safety" within a proscribed period of time, resulted in the transfer of numerous residents with dementia from assisted living.

To date, the term "transition" has been used in the gerontological and health services literature to denote relocation from one health care setting to another, or from home to a residential care setting (Hersch, Spencer, & Kapoor, 2003; Peete, 1999; Wilson, 1997). Relocation transitions involve moving from one place of residence to another, or from one

area within a current place of residence to another (e.g., from the independent living to the assisted living section of a continuing care retirement community). Personal health crises can represent an intrapersonal transition that necessitates changing one's habituated functional state of being. In some instances, intrapersonal transitions may result in a misfit between the individual and his or her current environment, and ultimately in the need for a relocation transition either into or from assisted living.

Unfortunately, relocation transitions and health crises are among the top 10 life stressors for people of all ages, but are especially stressful for older adults due to their association with loss and ultimately the end of life (Danermark & Ekstrom, 1990; Lander, Brazill, & Ladrigan, 1997; Rowles, 2000; Ryff & Essex, 1992; Thomasma, Yeaworth, & McCabe, 1990). Other more subtle types of intrapersonal transitions, such as the gradual loss of cognitive, communicative, and functional abilities associated with advancing dementing illness, and their relationship to relocation transfer of assisted living residents, have not been thoroughly discussed in the literature. This lack of attention is of concern because negotiating transitions, and transitional care, can be especially difficult for persons with dementia and their families (Bredin & Kitwood, 1995; Dehlin, 1990; McAuslane & Sperlinger, 1994; Robertson, Warrington, & Eagles, 1993). Consequently, recognizing and understanding the complex transactions between residents with dementia, their families, and facility caregivers in relation to retention and transfer from assisted living is highly important.

This study uses a qualitative ethnographic approach including participant observation combined with informal and formal face-to-face interviews to explore the decision-making process regarding retention or transfer of persons with dementia. Further, to the extent the data allow, it aims to examine the behavior and environment interaction theme proposed by Aud (2000, 2002) and to shed light on the seeming contradiction between the reasons for discharge found by Hawes and colleagues (1999) and the existence of large populations of residents in assisted living who have moderate to severe cognitive impairment, exhibit behavioral problems, and/or require increased care found by Zimmerman, Sloane, Eckert, Buie, and colleagues (2001). Unlike prior studies that relied on cross-sectional structured interviews of assisted living facility administrators, this study provides an in-depth longitudinal multivocal perspective derived from repeated interviews and observations of multiple parties (administrators, managers, staff, family members, and residents) collected over an extended period of time (approximately 6 months) in each facility. It is based on analyses of 101 field notes and 89 ethnographic interviews of 62 study participants in three assisted living facilities collected during a 21-month period. Quantitative methods do not allow for this type of in-depth understanding of complex issues.

Design and Methods

The Transitions from Assisted Living: Social and Cultural Aspects study (the Transitions Study) is part of a larger family of studies known as Collaborative Studies of Long-Term Care (CS-LTC). The central aim of the Transitions Study was to examine social and cultural aspects of transitions into and out of assisted living facilities in Maryland. The design called for sequential ethnographies lasting 5 to 6 months to be completed in each facility. Data for these analyses were collected between April 2002 and December 2003 in three facilities reflecting two of the CS-LTC facility strata: those with less than 16 beds (two facilities) and one "traditional" facility. A traditional facility has 16 beds or more but is not indicative of a "new-model" facility that caters to a more impaired population; in lay terms, it is similar to board-and-care-style long-term care. Details of the CS-LTC facility strata can be found elsewhere (Zimmerman, Sloane, & Eckert, 2001).

Data Collection

Two PhD-level ethnographers and two gerontology doctoral students conducted participant observation and ethnographic interviews with residents, residents' family members, facility owners, administrators, and managers, staff, and third-party health care providers. During active fieldwork in each facility, data collectors were on-site for a minimum of 8 hr per week in the smaller facilities and 16 hr per week in the traditional facility. Periodic follow-up consisted of bimonthly telephone conversations with the facility manager and on-site visits as needed to track new transitions as they occurred.

Participant Observation

The field team observed activities and interacted with residents, family members, and staff in the public areas of the facility. Each ethnographer compiled her own field notes. Members of the field team often were on site simultaneously, allowing corroboration of the individual observations and insight into the same event as seen from two perspectives. This procedure was particularly important with regard to observations of those residents with dementia who communicated nonverbally and could not participate directly in formal ethnographic interviews.

Ethnographic Interviewing

Ethnographic interviewing allows the researcher to capture the personal experience of participants and was used for all interviews. This method empowers informants to discuss experiences in their own terms. It permits understanding or exploration of the social actors' perspective, definitions, and experiences and

uses the informant's naturalistic utterances as new starting points for additional inquiry (over those supplied by the interviewer) and discovery.

Ethnographers used sets of qualitative entry questions to elicit initial common responses from all informants, followed by reflexive probes and follow-up items tailored to prior responses. All interviews were tape-recorded and ranged in length from approximately 20 min to 5 hr. In some instances, individuals were interviewed multiple times over a period of months. Resident interviews were conducted in designated areas of the assisted living facilities where privacy could be assured. The draft transcript and tape recordings were reviewed by the ethnographic interviewer and edited as needed prior to submission of the document for review by the investigative team.

Data Analysis

A collaborative coding methodology was used for this project. Hardcopies of all documents were distributed to coding teams, consisting of two project team members (investigators and research assistants). Each individual coded each document independently using a code list that emerged inductively from investigator review and discussion of documents produced by the field team. The two coders then met to jointly create a master copy reflecting their reconciliation of coding differences. Unresolved coding issues were brought to biweekly project team meetings and the code list was reviewed, critiqued, and revised as necessary. Each ethnographer served as a member of the coding teams, but did not code any documents that she created. All documents and codes were entered into Atlas.ti, version 4.2 (Scientific Software Development, 1998) for analysis.

To capture issues related to residents with dementia, Atlas.ti queries were run for each of the following codes: dementia or cognitive impairment, problematic or inappropriate behavior, and transitions. In this way, dementia was loosely defined in accordance with how the term and such residents were categorized by respondents. Textual analysis for themes associated with transitional care of residents with dementia by resident, facility, and across facilities was performed on all documents and portions of documents resulting from the Atlas.ti queries.

Results

Information about the three facilities and respondents in this study is provided in Tables 1 and 2. The two smaller facilities are in a suburban setting; the traditional one is in a rural setting. All are privately owned, for profit, and serve an elderly clientele. The most notable difference, reflective of the sampling design, is the larger number of beds in the traditional facility (Facility 3) compared to the smaller facilities (34 vs 6–8).

Table 1. Facility Characteristics

Characteristic	Facility 1	Facility 2	Facility 3
Type[a]	< 16 beds	< 16 beds	Traditional
Structure	Single story	Two story	Commercial
Setting	Suburban	Suburban	Rural
Ownership	Private	Private	Private
Profit status	For profit	For profit	For profit
Facility age (years)	7	14	15
Licensing	6 beds	8 beds	34 beds
Rooms	Private	Semiprivate	Private
Nonadministrative staff	1	1	31
Resident age	79–96	70–88	70–103

[a]Type refers to categories established by the Collaborative Studies of Long-Term Care (CS-LTC; Zimmerman, Sloane, & Eckert, 2001). These categories are "small" (facilities with < 16 beds), "traditional" (facilities with ≥ 16 beds that do not meet the criteria for "new-model"), and "new-model" (facilities with ≥ 16 beds built after January 1, 1987, and that meet at least one of the following additional criteria: offer 2 or more private pay monthly rates, > 20% of residents require transfer assistance, > 25% of residents are incontinent daily, have RN or LPN on duty at all times).

Overall, data sources consisted of 101 field notes and 89 ethnographic interviews with 62 different individuals. Data were collected specific to 29 residents with dementia, and also about the issues under study, more generally. The majority of respondents were female (79%) and White (85%). Only 5 of the interviewees were Hispanic. Approximately one third of respondents were residents, one third were family, and one third were facility staff or other professionals. Reflective again of the larger pool in Facility 3, two thirds of all data were derived from that facility.

All of the facilities admitted residents with dementia and reported retaining at least some of these residents over a period of several years, during which time their dementia worsened noticeably. Some residents with dementia were admitted but not retained in these facilities and some potential residents with dementia were never admitted to the facilities. During initial interviews, facility administrators articulated retention or transfer criteria regarding residents' degree of cognitive impairment, specific types of dementia-related behavioral problems, and level of care needed. Based on these interviews, it appeared that strict, unyielding decision-making criteria existed; however, observations and interviews with other parties showed that implementation of these decision-making standards was individually applied, thus appearing inconsistent and sometimes contradictory.

Findings indicate that problematic behaviors, such as wandering, agitation, incontinence, and dependence in activities of daily living, were common among the residents with dementia in these facilities. Also, many of these behaviors and residents' ability to communicate successfully were reported to change during the 6 months of data collection, although subtly. Furthermore, although they were a source of

Table 2. Study Participant Sample (N = 62)

Participants	Facility 1	Facility 2	Facility 3
Total number of study participants	12	8	42
Resident	1	1	21
Female	1	1	20
Male	0	0	1
Caucasian	1	1	20
African American	0	0	1
South Asian	0	0	0
Pacific Islander	0	0	0
Hispanic	0	0	0
Non-Hispanic	1	1	21
Family	6	4	10
Female	5	3	2
Male	1	1	8
Caucasian	4	4	10
African American	2	0	0
South Asian	0	0	0
Pacific Islander	0	0	0
Hispanic	3	1	1
Non-Hispanic	3	3	9
Administrator	2	1	1
Female	2	1	0
Male	0	0	1
Caucasian	0	0	1
African American	0	0	0
South Asian	2	0	0
Pacific Islander	0	1	0
Hispanic	0	0	0
Non-Hispanic	2	1	1
Care staff	1	2	10
Female	1	1	10
Male	0	1	0
Caucasian	0	0	10
African American	1	0	0
South Asian	0	0	0
Pacific Islander	0	2	0
Hispanic	0	0	0
Non-Hispanic	1	2	10
Other professional	2	0	0
Female	2	0	0
Male	0	0	0
Caucasian	2	0	0
African American	0	0	0
South Asian	0	0	0
Pacific Islander	0	0	0
Hispanic	0	0	0
Non-Hispanic	2	0	0

stress for assisted living facility managers, staff, and family members, no one type of dementia-related behavioral or communicative transition was uniformly associated with either intra- or inter-facility relocation transitions. That is, development of mild dementia and/or advancement to moderate or severe stages of dementia while in residence did not emerge as explanatory themes for relocation transitions. In fact, most of the interfacility relocation transitions were associated with non-dementia-related health crises, as

was true for the nondemented residents of these facilities as well. Further, no state or local regulations per se appeared to influence transitions and transitional care of residents with dementia in the study facilities.

Instead, stories of "who," "how," and "why" residents with dementia transitioned within and from these assisted living facilities revealed four predominant themes related to how transitions were perceived and decisions were made—the facility manager, the resident's care needs, family member's involvement and willingness to work with the facility to provide care, and the degree to which the facility environment is dementia-friendly (i.e., able and willing to accommodate the changing needs of individual residents with dementia, mediate resident transitions, and influence the manner in which residents with dementia's increasing needs for care are or are not accommodated by the facility).

Theme 1: Facility Manager's Pivotal Role in Determining the Timing of Transitions

The manager of each of the study facilities had substantial experience running an assisted living facility and had been the sole manager of the facility throughout its operation. He or she was the pivotal figure on whom relocation transition decisions depended. The theme of the manager's influence appeared in the form of stories told about the processes by which individual residents with dementia were admitted to the facility, assisted during the settling in period, accommodated as the dementia worsened, and were either retained or transferred from the facility. These stories about the manager's pivotal role were told by the managers themselves, assisted living staff, family members, residents, and other health care professionals. One manager, for example, expressly noted that aging-in-place is not guaranteed, when discussing her decision to transfer a new resident.

> "That's why I always tell them. I don't guarantee them anything, even if you sign the papers that I have to keep them for one year. I tell them, if I cannot take care of them, if they become destructive, they hurt themselves or somebody else, or are being combative, they have to go."

The managers also reflected on the influence of market conditions and staff retention issues on their decision making regarding potential transitions of residents with dementia.

Theme 2: Care Requirements Related to Transitions

Beliefs about what constitutes dementia, its causes, probable outcome, viable treatments, and expectations regarding the capabilities of persons

with dementia varied widely among study participants. Among those interviewed, the assisted living managers, third-party case managers, and a registered nurse had more formal training and greatest understanding of dementia and dementia care than did residents and family members; however, only one of the three managers had familiarity with differential diagnosis of dementing illnesses and associated treatment protocols. Most staff members defined dementia as memory loss only, associated it with normal aging, and generally did not believe that it required transition from the facility; however, staff members were aware of the care needs of residents with dementia.

> "She is becoming total care, which eventually she will have to be put in a nursing home. She needs a lot of attention. Basically we have got to keep up because when she goes to the bathroom, she don't wipe herself, so we have to do it for her. We have to basically give her—we have to dump the meds into her mouth, otherwise she won't. She is just becoming total care . . .. Some of it is from dementia. The rest of it is laziness. Most of the residents that I have up here have dementia—starting into Alzheimer's, it's not complete Alzheimer's—it's more dementia."

In contrast, problematic or inappropriate behaviors, such as undressing in public areas, verbal and physical agitation, and wandering, despite being associated with worsening dementia, were not ascribed to normal aging. All three assisted living managers screened potential incoming residents for these behaviors and denied admission if they were apparent. Care responses to and decision making regarding transitions of already admitted residents who displayed these behaviors varied greatly, often reflecting either the assisted living manager and/or staff's emotional attachment to particular residents, the family members' influence, or occasionally deference to the wishes of other residents.

Theme 3: Family Involvement Influencing Care and Transitions

The manner in which family members participated in the care of and decision making for residents with dementia varied. The family members who participated in this study were those persons who had been the primary caregiver prior to admission and remained in active contact. These family members had commonly observed the onset of dementia, sought diagnosis, treatment, and care prior to assisted living placement, ultimately decided when it was time for placement, selected the assisted living facility, and engineered the actual admission procedure. The residents had varying degrees of involvement in decision making regarding these processes and their timing. Family members included sons, daughters, siblings, nephews, nieces, grandchildren, fictive kin, and their spouses.

After assisted living placement, family roles consisted primarily of regular visitation, oversight of care provided by staff and third-party health care providers, arrangement of and transportation to and from medical appointments, receipt and delivery of residents' medications (in some facilities), advocating for the resident, and working with the facility manager and staff to lessen the number of instances and severity of the resident's problematic behaviors. These family interventions often were cited as key to averting transitions from assisted living.

In addition, family members frequently engaged in second-guessing previous placement choices and attempted to predict likely outcomes of potential transitions into and out of the study facility. For example, two key family concerns voiced in this study were (a) the fit between the resident's current ability to participate in activities and the level and type of activities provided by the facility, and (b) making the right choice regarding return to the assisted living facility versus entering a nursing home following discharge from a hospital or rehabilitation facility. Family members indicated acceptance of the facility manager as the ultimate decision maker with regard to the resident's potential discharge, noting that they trusted the manager to make a sound decision when the time came. Although they indicated that they would prefer to have the resident with dementia age in place in assisted living, the family members we interviewed did not expect this to happen. However, family members did recognize and exert their influence regarding the timing of transitions from assisted living and intrafacility transitions, such as room reassignments and relocation from general assisted living to a dementia-specific unit within the same facility. Family members even used tactics such as offering to incur additional expense in order to forestall a relocation transition.

> "I'll buy an aide because I don't want to move her. I love her with Amy [the assisted living manager], and I want her to stay there with Amy. But I don't want her to be locked up, even at Amy's . . .. That's why I told Amy, that if she needed another aide to, like, sit outside with her and take her for walks, do that kind of stuff, I would do that because it would be worth it to keep her where she is to me to do that. So, no, I'm not second guessing myself about the place, but I'm worried that I might have to make another move because her disease [Alzheimer's] is going to go. It just depends I guess on how rapidly her disease goes."

Theme 4: Dementia Friendliness of Facility Culture in Relationship to Transitions

Each assisted living facility had its own distinct culture. Following Geertz (1973), in this study the

term "culture" refers to "webs of significance" or, more specifically, the tacit and overt assumptions that frame experience and the meanings ascribed to them (p. 5). Facility cultures are dynamic and change over time. Each facility's culture was dementia friendly to some extent; however, the facilities were markedly more dementia friendly toward their existing residents and families than they were toward potential new residents. For example, when a long-time resident became incontinent, refused to cooperate with staff attempts to manage her incontinence, and did not wish to relocate downstairs, the manager took a more person-centered approach.

> "I have a different—not philosophy—I have a different take on it. Have we had to go in there and had her carpet cleaned? Yes. Could I have put her downstairs where we have the tiles so if she does that, we just wipe up the tiles? Put a bedpan on the chair and get her, like, a duster to wear, which is more like what she wears? You know, I could have done that. I could probably do that at any time, or tell the family if they refuse, although I don't think they would. But if they refuse, the one that is going to refuse is her, and out she goes. But again, I try to be more liberal …. Another place like us is not going to tolerate it. They are going to put her in a diaper and if she doesn't they are going to give 30 days notice to get out. I mean, I am much more liberal than a lot of places, in trying to let these people enjoy what time they have left and not put too many rules and constraints on them."

Dementia friendliness often was framed as references to whether or not an individual resident "belongs here" or "is one of us." Facility culture dictated who sat with whom in the dining room or other public areas and the "punishments" meted out to transgressors of facility norms.

At a more subtle level, facility culture dictated when tacit agreement had been reached that the facility was going to, or in fact already had, transformed from an assisted living facility providing housing and care to a predominantly cognitively intact population to a largely de facto dementia assisted living facility. Each facility, but especially the smaller facilities, also had to grapple with changes in its culture resulting from its residents becoming increasingly demented. Culturally defined behavioral norms and assisted living staff and manager's roles and daily activities changed in the face of advancing dementia. These changes in turn influenced decision making regarding possible transitions from the facility.

Ultimately, each facility culture was also impacted by death, the final transition from assisted living. During our study, no resident with dementia, non-demented resident, nor assisted living staff member died on-site; however, several died off-site. In one case, the resident with dementia had been one of the facility's original residents, lived in the facility for almost 7 years (including several years during which she was severely demented), and was retained by the facility until two days prior to her death at which time she was transferred to the acute care hospital in which she died. Each facility dealt with issues surrounding communication with residents with dementia regarding deaths of other residents and assisted living staff in its own way. For example, the managers of the two small facilities opted not to share information about deaths with residents with dementia, indicating that they did not believe these residents would remember their former coresidents or even notice they were no longer residing there; they were concerned the residents would be unnecessarily upset by the news of the death. The traditional facility's culture was more open about sharing information with both its demented and nondemented residents.

Discussion

By conducting extensive ethnographic fieldwork over many months and listening to the voices of multiple parties affiliated with each assisted living facility, this study has explored the meanings and decision-making process associated with retention and transfer of residents with dementia. All three facilities under study routinely retained residents with moderately severe cognitive impairment. Although none of these facilities were willing to admit residents with severe dementia, two facilities retained individual residents even after they developed severe dementia. Decisions regarding retention or transfer of residents with dementia who were dying were made on a case-by-case basis. Keyword and thematic analysis of more than 200 block quotations coded dementia or cognitive impairment, problematic or inappropriate behavior, and transitions revealed four important themes associated with resident relocation and intrapersonal transitions. These themes are the facility manager, resident care needs, family member's involvement and willingness to work with the facility to care for the resident, and the extent to which the facility culture is dementia-friendly—that is, able and willing to accommodate the changing needs of residents with dementia. By reading the narratives associated with these four themes it is possible to gain a better understanding of the manner in which the needs of residents with cognitive impairment, dementia-related behavioral problems, and increased needs for care are accommodated by these facilities.

While the finding that resident care needs relate to transitions has been reported by others (Hawes et al., 1999), and the importance of the role of the family in assisted living is becoming evident (Port et al., 2005, this issue), little has been written about the role of the manager and the assisted living facility culture—both overall and in relation to influencing transitions for residents with dementia. Assisted living managers in both this study and the Hawes study (Hawes,

Phillips, Rose, Holan, & Sherman, 2003) added an "it depends" qualifier to their responses concerning the criteria for retaining or transferring residents with dementia. They treated "it depends" as "no" because they felt that residents and family members who were concerned about these criteria could not rely on admission or retention in these facilities. However, Hawes and colleagues also noted that these facilities' criteria are likely products of the resident case-mix they desire and the market niche they wish to pursue. Aud (2000, 2002) suggested that the interaction between resident behaviors and the assisted living facility environment (defined as the physical nature of the facility, location, site features, state regulations, facility services, program, and staffing) is the key decision-making criterion for retention or discharge of residents with dementia. Aud described the retention or transfer decision-making process as a linear direct cause and effect sequence in some instances and as a balancing of needs versus factors in others. While this study's findings support both Hawes and Aud's, they go a step further. Most notably, these findings highlight the human component integral to assisted living decision making and the realization that decisions are in fact individualized and dependent on multiple factors. The decision whether to retain or transfer seems to be based on the assisted living manager's perception of the existing facility culture, the specific care requirements related to dementia (and the facility's ability to address them), and the role of the family; these factors seem to lie at the heart of the "it depends" qualifier.

To date, the terms assisted living manager and administrator have been used interchangeably in both the practice and research literature. Oftentimes in practice, one person fulfills both roles, as was true in two of the study facilities. In the third, the manager and the administrator were sisters, worked closely with each other and with the residents and families, and exhibited virtually identical responses to resident care and transition dilemmas. However, in other facilities this may not be the case, especially in the case of new-model facilities that are parts of corporate chains. The separate influence of assisted living managers and administrators on decision making regarding resident transitions has not yet been explored and may well merit attention if the key authority is a prescribed policy that does not recognize the "it depends" of each individual resident.

Indeed, Allen (1999) notes that administrators "give life" to the assisted living philosophy by organizing the resources and finances to meet resident needs. In our three facilities, the on-site administrator or managers retained the ability to set, interpret, and implement admission or discharge and intrafacility relocation policies for persons with dementia. This structure accorded them much latitude in decision making and accommodating the perspectives of a large number of players (i.e., the resident with dementia, other residents, family members, staff, other health care professionals, and outside regulators). Together, they were able to develop individualized solutions for handling problematic resident behaviors and retaining residents with dementia as they progressed through the disease process. In larger corporate-owned facilities, however, administrative responsibilities may be split between board members, administrators, care coordinators, and others, some of whom may work off-site. Further, policies for these facilities may be set off-site by upper echelon administrators in consultation with the corporate board of directors, and then uniformly applied to assisted living facilities operating in widespread geographic areas. This "top-down" management could certainly influence decision making regarding retention and transfer of persons with dementia. In such instances, it seems more likely for decisions to be influenced by market forces (the need to keep beds filled, which may or may not be favorable to retaining residents with dementia) than by a truly person-centered focus.

Similarly, the administrator or manager's awareness of external labor and market conditions may lead him or her to focus attention on the effects of staff burden from caring for assisted living residents (i.e., staff turnover), or on one segment of the resident population over another. In doing so, a tone is set for the facility, which manifests itself in the facility culture and decision-making processes. In our study, all three managers modeled great compassion and concern for residents and their family members and exhibited manager-centered leadership; however, they varied in their awareness of and response to outside labor and market conditions. The Facility 1 manager's decision making regarding retention or transfer of persons with dementia was least affected by these conditions, whereas the Facility 2 manager was concerned about market conditions and the type of residents she would be able to attract if she retained particular residents. The Facility 3 manager was more influenced by labor conditions, favoring protecting and meeting the needs of his staff over those of individual residents.

In this way, the dementia friendliness of a facility's culture also was influenced by the manager's awareness of external labor and market conditions. Both admission and transfer decisions were influenced by the presence of other assisted living facilities in the geographic area. For example, the Facility 2 manager had not intended to provide housing and care for persons with dementia when she opened her facility 14 years ago; however, she noted that as more assisted living facilities opened in her area, increasingly those seeking admission were persons with mild to moderate dementia. In order to keep her facility operating at maximum or near-maximum capacity, she found it necessary to admit and retain persons with increasingly severe dementia. The resultant facility culture became dementia friendly to the extent that persons with dementia who could safely ambulate

up and down stairs and did not wander off premises were allowed to remain in residence. The Facility 1 manager's admission and retention or transfer decision making reflected her sensitivity to another aspect of market conditions: the difficulties that family members in her geographic area faced in finding high quality care for persons with dementia at an affordable price. Her response was to retain residents with severe dementia, transforming the facility's daily mode of operation to meet the changing needs of these residents. The resultant facility culture was focused on provision of highly individualized care that enabled residents to age in place in the facility. Facility 3's manager and staff proudly noted that the facility cared for persons whom no one else would take. The result was a facility culture in which persons with dementia comingled with nondemented residents and with residents with mental illness. Behavioral eccentricities were tolerated and/or actively managed by both pharmaceutical and nonpharmaceutical means, to retain this case-mix.

All three facility cultures were dementia friendly if one interprets that phrase as referring to admission and retention of persons with dementia with differing and changing needs. Each facility's philosophy of care was person-centered to the extent that it allowed individualization of care. However, if a dementia-friendly facility culture is defined as one that enables each person with dementia to achieve and maintain his or her highest possible level of physical, mental, emotional, and spiritual well-being throughout the course of the dementing illness, then all of these facilities were lacking in some respects. While the manager of Facility 3 appeared to understand many issues related to dementia, the staff had not been taught how to assess and treat various manifestations of the illness and how to tailor their interventions accordingly. The culture of Facility 2 was based on group activities chosen without regard for individual residents' particular likes and talents, allowing only minimal accommodation for particular interests. Facility 1's culture was compassionate and concerned for the needs of individual residents, family, and staff, but provision of dementia-friendly care and decision making were hindered by a uniform lack of knowledge regarding viable treatment options for persons with dementia, the unique manner in which persons with dementia often express physical pain and discomfort, and ways in which to assist persons with dementia in positive expression of their latent abilities.

This situation may be remedied, at least in part. Many assisted living managers and staff are licensed professionals who are required to participate in continuing education in order to retain their licenses. Training, such as that provided through the Alzheimer's Association's Campaign for Quality in Residential Care, offers dementia-care instruction for all levels of assisted living staff. However, challenges to training must first be addressed. Of note, small facilities often lack sufficient surplus funds to cover the cost of continuing education and may experience difficulty obtaining qualified temporary relief staff while they attend such programs. Policies that would allow small facilities to pool their resources to contract for outside services and qualify for group discounts for training could help them provide care and ultimately reduce relocation transitions for residents with dementia.

Admittedly, the three facilities under study are a small sample and are unique in that all of them have been overseen by the same manager for their entirety. It is feasible that the importance of both the role of the manager and the facility culture—which undoubtedly reflects the manager's influence—may be markedly different in a facility that has experienced turnover in leadership. Considering that administrator turnover in long-term care averages 43% annually (Castle, 2001), it is advisable to explore this issue in a wider range of facilities. Indeed, all of the findings presented are limited due to small sample size (three facilities) and may not be generalizable to other facilities, particularly those with a different administrative structure. Future research is needed to expand the sample to include more small and traditional facilities as well as larger new-model ones in order to ascertain whether more bureaucratic management structures are associated with increased relocation transitions for persons with dementia. Some recent work by Zimmerman and colleagues (2005) suggests there may indeed be a tendency (albeit not statistically significant) for new-model assisted living to transfer more often, although these findings are not specific to residents with dementia. In addition, multisite studies of facilities in different geographic areas are needed to further understand the multifaceted issue of transitions for residents with dementia.

While residents with dementia and their families were aware that the assisted living facility may not be the older adult's final place of residence, few individuals who participated in the study relished relocation. Thus, staff, residents, and families could benefit from greater understanding of the manager's pivotal role and its intertwinement with family involvement and facility culture as determinants of potential transitions. Given the often-seen propensity to fail to hear and/or to disregard the voices of residents with dementia (Barnett, 2000; Cotrell & Schultz, 1993; Goldsmith, 1996), heightened sensitivity of assisted living managers and family members to these three factors is even more critical. Considering and specifying criteria that potential assisted living residents and their family members might use to assess the fit between current and future needs of residents with dementia and the likelihood of a particular facility's being able and willing to accommodate these changing needs could assist placement decisions. Most notably, clarifying the role of the family and their ongoing involvement

may be especially helpful in the planning process. Work presented in this issue (Port et al., 2005) indicates that families are indeed involved in assisted living care, and so they may well appreciate understanding the true importance of their ongoing caregiving.

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Health and Functional Outcomes and Health Care Utilization of Persons With Dementia in Residential Care and Assisted Living Facilities: Comparison With Nursing Homes

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Purpose: This study compares health and functional outcomes and health care utilization of persons with dementia residing in residential care/assisted living (RC/AL) facilities and nursing homes. **Design and Methods:** The study uses data from a longitudinal cohort study of 1,252 residents with dementia in 106 RC/AL facilities and 40 nursing homes in four states. **Results:** Rates of mortality; new or worsening morbidity; and change in activities of daily living, cognition, behavioral problems, depressive symptoms, social function, and withdrawal did not differ between the two settings. However, because of death or transfer, only about one half of the persons with mild dementia and one third of those with moderate to severe dementia remained in RC/AL facilities 1 year after enrollment. In addition, hospitalization rates were greater among individuals with mild dementia in RC/AL facilities, largely because of a medically unstable subgroup with high nursing-home-transfer rates. **Implications:** Many persons with dementia can be served equally well in either setting; however, those with major medical care needs may benefit from nursing home residence.

Key Words: Alzheimer's disease, Outcomes, Nursing homes, Assisted living, Residential care, Special care units

Nursing homes have traditionally served the vast majority of institutionalized persons with Alzheimer's disease and related dementias; however, recent years have seen rapid expansion of residential care–assisted living (RC/AL), a model of care that claims to emphasize resident independence, autonomy, dignity, and privacy (Mollica, 1998; Zimmerman, Sloane, & Eckert, 2001). Over the past two decades, RC/AL has grown from a concept to an industry that cares for 1.25 million of America's elderly persons in more than 36,000 facilities nationwide (Galloro, 2001; Mollica, 2002; Sullivan, 1998). The opportunity for cost savings (Leon, Cheng & Neuman, 1998; Leon & Moyer, 1999) by using these facilities in place of nursing homes has put pressure on states to provide Medicaid funding for RC/AL, and, by 2003, 41 states provided some public funding for RC/AL (Mollica, 2002). Currently, approximately 60% of nursing home residents and nearly 40% of RC/AL residents suffer from some form of dementia (Magaziner, Zimmerman, Fox, & Burns, 1998; Mollica, 2001; Sloane, Zimmerman, & Ory, 2001; Sullivan), and nearly three fourths of individuals with Alzheimer's disease spend some time in one or another of these settings (Welsh, Walsh, & Larson, 1992).

Despite the recent growth of RC/AL, to our knowledge no large study has examined whether dementia care in these settings differs from that

provided by nursing homes. Proponents of RC/AL claim that it provides a homelike atmosphere that may help maintain function, promote independence, improve resident outcomes, enhance family and staff satisfaction, and improve quality of life (Saxton, Silverman, Ricci, Keane, & Deeley, 1998). Others have noted, however, that because RC/AL homes often lack professional staff, they may not adequately address functional status needs, depression, comorbid conditions, and other causes of morbidity and mortality among persons with dementia (Pruchno & Rose, 2000). As a further complicating factor, specialized dementia care units and facilities have proliferated in RC/AL, adding one more subquestion to the debate (Davis et al., 2000).

Given that RC/AL and nursing homes often serve dementia residents with similar characteristics (Davis et al., 2000), an important policy and practice question is the extent to which outcomes of care may differ across settings. Among the outcomes of interest are mortality, rates of decline in functional status, and the incidence of new health events such as decubiti and infection (Galasko et al., 1995; National Institute on Aging/National Institutes of Health [NIH], 1999). In this article we compare health and functional outcomes and health care utilization of persons at similar stages of dementia, using data from a large, multistate cohort study of RC/AL facilities and nursing homes.

Methods

Participants

In these analyses we describe the 1-year outcomes of participants with dementia who were enrolled in the Collaborative Studies of Long-Term Care (CS-LTC), a longitudinal cohort study of a stratified random sample of RC/AL facilities and nursing homes in Florida, Maryland, New Jersey, and North Carolina. We chose the four states, after consulting with national experts and reviewing state regulations, because each had a well-developed RC/AL sector, and the four states varied in their regulatory approaches to the term *assisted living*. At the time, Florida contained nearly 10% of all such beds in the nation; North Carolina had the greatest Medicaid support for residents at this level of care; New Jersey was the third state in the nation to implement an Oregon-type "assisted living" licensure category; and Maryland's regulations were less developed than those of the other three states (Zimmerman, Sloane, Eckert, Buie, et al., 2001). The study defined RC/AL as all residential long-term care facilities licensed by the states at a non-nursing-home level of care that provided room, board, 24-hr oversight, medication administration, and assistance with activities of daily living. This definition of assisted living included three separate facility licensure

categories in both Florida and New Jersey and two categories in both Maryland and North Carolina, five of which (all in NC and MD and one in NJ) were specifically designated as "assisted living" by state regulations.

To ensure adequate representation of the range of RC/AL types across the study states, we randomly sampled facilities in four strata and selected residents by using a strategy that was designed to enroll approximately equal numbers of participants in each stratum. The four sampling strata were (a) small (< 16 beds) RC/AL facilities; (b) new-model RC/AL facilities (≥ 16 beds, built after 1986, and with at least one of the following features of newer, health service intensive RC/AL: charges that varied by resident service need, having ≥ 20% of residents who required assistance in transfer, having ≥ 25% of residents who were incontinent daily, or having a licensed nurse on duty 24 hr/day); (c) "traditional" RC/AL facilities (≥ 16 beds, not meeting the new-model definition); and (d) nursing homes. We defined dementia special care units as areas within facilities (or entire facilities) that were self-designated as Alzheimer's or dementia units, and within which at least three fourths of the residents had a diagnosis of Alzheimer's disease or a related disorder. The facility recruitment rate was 59%; nonparticipating facilities did not differ from participating ones in proprietary status, age, size, or occupancy rate, or resident age or ethnicity–race. Further details of the study design are provided elsewhere (Zimmerman, Sloane, Eckert, Buie, et al., 2001).

Within study RC/AL facilities, we enrolled a random sample of residents. Within nursing homes, we drew a stratified random sample with the goal of enrolling approximately equal numbers of persons with mild dementia (i.e., who were ambulatory and had a dementia diagnosis) and with moderate to severe dementia (i.e., had dementia and required physical assistance with ambulation, transfer, or feeding); thus, enrollment criteria within nursing homes excluded individuals undergoing rehabilitation and oversampled ambulatory persons with dementia. Across facility types the recruitment rate for eligible resident participants was 92%. Each facility received an on-site data-collection visit on enrollment in the study (October 1997 through November 1998), during which a variety of facility- and resident-level data were obtained. Subsequently, we had each facility telephoned quarterly for 1 year to identify the incidence of new health events and changes in a variety of psychosocial and functional measures for each enrolled resident. Participants who were permanently transferred out of study facilities were censored at the time of discharge; in these cases, we gathered medical, functional, and health care utilization data about their status prior to discharge. This study was approved by the Institutional Review Board of the University of North Carolina at Chapel Hill.

Selection of Participants With Dementia

These analyses involved the 1,252 CS-LTC participants from 206 facilities who, on enrollment, met study criteria for dementia and whose level of dementia (mild, moderate, or severe) could be determined. We defined dementia to be present if, at baseline, (a) the medical record reported a diagnosis of Alzheimer's disease, senile dementia, organic brain syndrome, cerebral arteriosclerosis, multi-infarct dementia, subcortical dementia, Binswanger's disease, Pick's disease, Creutzfeldt-Jakob disease, Lewy body disease, or unspecified dementia; and (b) the participant received a score of ≥ 2 on the Minimum Data Set Cognition Scale (MDS-COGS; Hartmaier, Sloane, Guess, & Koch, 1994), which is roughly equivalent to a Mini-Mental State Examination score of < 23 (Gruber-Baldini, Zimmerman, Mortimore, & Magaziner, 2000; Hartmaier et al.). We assigned severity of dementia on the basis of impairment of three activities of daily living (ADLs): locomotion, transfer, and feeding. We classified participants meeting the study diagnosis of dementia who were independent in all three of these ADLs as having mild dementia; we classified those who required physical assistance with one or more of these ADLs as having moderate to severe dementia. This system of classification results in a moderate–severe category that roughly includes persons at stage 6 or 7 (severe or very severe cognitive impairment) on the Global Deterioration Scale (Reisberg, Ferris, de Leon, & Crook, 1982), stage 3 (severe dementia) on the Clinical Dementia Rating Scale (Hughes, Berg, Danzinger, Coben, & Martin, 1982), and a score of 5 or greater (moderate, severe, or very severe dementia) on the MDS-COGS (Hartmaier et al.). We excluded 30 enrolled participants with dementia from analyses because data were insufficient for us to determine the level of dementia.

Measures and Data Collection

Enrollment data were gathered on site by professional data collectors, the majority of whom were nurses. Follow-up data were gathered by telephone interview. All data collectors were trained and supervised by the study's principal investigators (P. Sloane and S. Zimmerman).

Data collectors collected basic demographic information on study participants, including age, gender, race or ethnicity, education, marital status, length of residence in the facility at baseline, and comorbid illness at baseline, from the resident or a staff member who was knowledgeable and familiar with the resident's health. For analysis purposes, we express comorbidity as a summary scale of the presence or absence of the following morbidities: peripheral vascular disease, congestive heart failure, hypertension, hypotension, myocardial infarction, other heart problems, Cushing's syndrome, diabetes, hyperparathyroidism, thyroid or other glandular disorders, pituitary disorders, blindness, glaucoma, cataracts, or macular degeneration, liver disease, chronic renal disease, stomach or intestinal ulcers, AIDS, arthritis, fracture, osteoporosis, Paget's disease, cerebrovascular disease, hemiplegia, paraplegia, dizziness or imbalance, seizures, mental retardation, Parkinson's disease, chronic pulmonary disease, cancer, and mental or psychiatric illness.

We had all measures for which change would be recorded over time collected at baseline from staff interviews, thereby allowing for the same individuals (or, in cases of staff turnover, their replacements) to serve as respondents for follow-up data collection. We used the following measures to assess change in participant function over time:

1. We measured ADLs by using items from the nursing home Minimum Data Set. Inter-rater reliabilities for individual items exceed .90 (Hawes et al., 1995). We scaled items by using the Morris long scale (MDS ADL), which adds the 0–4 ratings (0 = *independent or no assistance*; 4 = *total dependence*) on seven ADLs (bed mobility, transfer, locomotion on unit, dressing, eating, toilet use, and personal hygiene; see Morris, Fries, & Morris, 1999).
2. We assessed cognitive status by using the MDS-COGS, a 10-point scale that assesses the presence and severity of cognitive impairment and that correlates ($r = -0.88$) with the Mini-Mental State Exam, and that has sensitivity, specificity, and chance-corrected agreement (kappa) above .80 (Hartmaier et al., 1994).
3. We measured behavioral problems by using the short version of the Cohen-Mansfield Agitation Inventory (CMAI; Cohen-Mansfield & Billig, 1986), a 14-item scale that identifies the frequency (on a 5-point scale) of agitated behaviors over the past 2 weeks on the basis of staff report. The CMAI includes factors of physically aggressive and physically nonaggressive behaviors, and verbally aggressive and verbally nonaggressive behaviors (Miller, Snowdon, & Vaughn, 1995).
4. We recorded depressive symptoms by using the Cornell Scale for Depression in Dementia, an observer-rated scale of depressive symptomatology designed to rate depression in individuals with dementia. This scale is the only depression scale validated for long-term care populations with dementia; inter-rater reliability is $\kappa = .67$ and internal consistency is $\alpha = .84$ (Alexopoulos, Abrams, Young, & Shamoian, 1988).
5. We assessed social function in the preceding 7 days by using items such as going to the barber or beauty shop, attending senior adult day care, and working on a hobby. We derived information on participation in social activities from questions asked in an earlier study of residential care facilities (Dittmar, 1989; Dittmar, Smith, Bell,

Jones, & Manzanares, 1983). These 17 items on participation (yes or no) encompass active–passive, solitary–group, and residential–community activities (House, Robbins & Metzner, 1982).

6. We assessed social withdrawal with a seven-item scale of the Multidimensional Observation Scale for Elderly Subjects (Helms, Csapo, & Short, 1987), which measures contact with and interest in people, events, and activities.

We had baseline data collected during site visits to each of the study facilities. We had follow-up interviews conducted quarterly by telephone so that we could assess whether or not residents had died, been discharged (including date and destination of discharge), been hospitalized, or experienced any new or worsening morbidity during the quarter. We defined new or worsening morbidity as the incidence or worsening of fracture, infection, stroke or paralysis, bleeding from the stomach or bowel, diabetes, heart condition, or skin ulcer; we chose these morbidities because they are relatively common in long-term care and have risk factors that can be modified through medical or nursing treatment. At the 1-year interview, or when a participant had been discharged during the quarter, the interviewers also administered the study measures of ADLs, cognitive status, behavior, depressive symptoms, social function, and withdrawal, determining 1-year status or that immediately prior to discharge.

Analysis

We calculated descriptive statistics by using appropriate programs from the Statistical Analysis System (SAS Institute, 2000). We modeled rates of mortality, hospitalization, and the incidence of new or worsening morbidity by using repeated measures analysis, in which we used generalized estimating equations (Liang & Zeger, 1986) to fit a Poisson regression model. For analytical purposes, we combined all new or worsening morbidities. We used Cox proportional hazards models to generate p values for differences between mean time to death. We modeled functional change by using generalized estimating equations to estimate differences in means. In additional analyses we compared outcomes of dementia special care unit residents with non-unit residents in RC/AL and nursing facilities, controlling for baseline resident characteristics.

To adjust for baseline differences between the RC/AL and nursing home samples, we (a) analyzed all models in two strata by degree of ADL impairment (independent or with some impairment of locomotion, transfer, or feeding), and (b) adjusted all models for the following resident baseline characteristics: age, gender, race, marital status, education, length of stay, MDS-COGS, and number

of comorbid conditions. To adjust for differential selection probabilities among the three facility types, we had all outcome analyses incorporate sampling weights (i.e., statewide proportions of residents and facilities in each sampling stratum, be it small, traditional, or new model).

Results

Characteristics of Study Facilities and Residents

A total of 206 facilities contributed participants to these analyses. Of these, 166 were RC/AL facilities (93 small, 34 traditional, and 39 new-model type) and 40 were nursing homes. Compared with nursing homes, the RC/AL facilities were smaller (mean bed size 30 vs 116; $p < .001$), newer (mean age 12 vs 24 years; $p < .001$), and more commonly for profit (83% vs 58%; $p = .004$). RC/AL facilities also provided fewer health ($p < .001$) and social or recreational ($p < .001$) services than nursing homes. Within these facilities, the analytic sample included 783 residents of RC/AL facilities and 489 residents of nursing homes; all of these individuals met study inclusion criteria for dementia.

Table 1 compares the RC/AL and nursing home samples in terms of selected demographic and health status characteristics measured on study enrollment. The RC/AL sample of individuals contained a higher proportion of participants who were White, widowed, had at least a high school education, and had mild dementia; nursing homes housed more African Americans, more persons who were divorced or separated, and more individuals with less than an eighth-grade education. The mean length of stay of the nursing home cohort at the time of study enrollment (896 days) was longer than that of the RC/AL participants (725 days). On average, the individuals in RC/AL, when compared with the individuals in the nursing homes, exhibited less severe cognitive impairment, fewer comorbid conditions, fewer impairments of ADLs, more depression, better social function, and less withdrawal; we noted no difference between the groups in the prevalence of problem behaviors.

Disposition of Study Sample at 1 Year

Table 2 shows the disposition of study participants at 1 year by facility type and dementia severity. Crude mortality rates of nursing home residents were higher than those of RC/AL residents among both mild and moderate to severe dementia subgroups. However, the residential care facilities discharged nearly one fourth of both mild and moderate to severe residents to nursing homes, where subsequent follow-up was not conducted. In contrast, fewer than 10% of nursing home participants were discharged or otherwise lost to

Table 1. Characteristics of Participants on Study Enrollment, by Facility Type

Characteristic	Type of Facility		
	RC/AL (n = 773)	NH (n = 479)	p
Age, M (SD)	84.4 (6.9)	84.9 (7.5)	.195
Female, %	78.1	76.2	.426
Race, %			
Caucasian	92.1	80.5	.001
African American	5.2	17.8	.001
Other	2.6	1.5	.186
Marital status, %			
Married	13.8	15.3	.446
Widowed	73.3	65.4	.003
Never married	6.4	9.4	.045
Divorced or separated	4.8	9.0	.003
Education in years, M (SD)	12.3 (3.6)	11.0 (4.9)	.001
$\leq$ 8th grade, %	17.4	33.2	.001
9th–12th grade, %	44.7	37.8	.035
> 12th grade, %	37.9	29.0	.006
Dementia status, %			
Mild	70.6	50.7	.001
Moderate or severe	29.4	49.3	.001
Length of stay in facility (in days), M (SD)	724.8 (740.8)	896.0 (866.2)	.001
No. of comorbid conditions, M (SD)	3.6 (2.3)	4.4 (2.2)	.001
ADL impairment (MDS-ADL), M (SD)	7.6 (7.9)	11.9 (8.2)	.001
Cognition (MDS-COGS), M (SD)	5.3 (2.4)	5.7 (2.3)	.005
Behavior (CMAI), M (SD)	19.7 (7.3)	19.8 (7.1)	.821
Depression (CSDD), M (SD)	4.5 (4.8)	3.6 (4.6)	.001
Social functioning, M (SD)	5.1 (3.0)	4.2 (2.7)	.001
Withdrawal (MOSES subscale), M (SD)	18.0 (6.2)	20.4 (5.6)	.001

Notes: RC/AL = residential care/assisted living; NH = nursing home; ADL = activity of daily living; MDS = Minimum Data Set; COGS = cognition; CMAI = Cohen-Mansfield Agitation Inventory; CSDD = Cornell Scale for Depression in Dementia; MOSES = Multidimensional Observation Scale for Elderly Subjects.

follow-up. As a result of death and transfer, only 52% of persons with mild dementia remained in RC/AL facilities after 1 year, compared with 71% of individuals at similar levels of dementia who resided in nursing homes at study entry. Among those with moderate to severe dementia, only 38% of the RC/AL cohort remained in the facility after 1 year, compared with 63% of the nursing home cohort.

Mortality, Hospitalization, and New or Worsening Morbidity

Table 3 displays the adjusted rates of mortality, hospitalization, new or worsening morbidity, and functional change for the RC/AL and nursing home cohorts, stratified by dementia status. To control for baseline differences between these cohorts, we adjusted for baseline age, gender, race, education, marital status, length of stay on enrollment, cognitive status, and number of comorbid conditions in all analyses. Rates of mortality, hospitalization, and new or worsening morbidity are displayed per 100 residents per quarter, because quarterly follow-up data-collection interviews recorded the presence or absence of health events during the reporting period. These adjusted results identify no significant difference in mortality or incidence of new or worsening morbidity between RC/AL facilities and nursing homes for either individuals with mild dementia or moderate to severe dementia. Hospitalization rates were, however, significantly higher among RC/AL residents with mild dementia than among nursing home residents of similar dementia severity.

To further investigate the relationship between hospitalization and facility type, we studied the rates of hospitalization and new or worsening medical morbidity separately for RC/AL residents who, during the follow-up period, were (a) subsequently transferred to nursing homes (n = 179) and (b) retained in the facility (n = 558); we combined mild and moderate to severe subgroups for these analyses. The hospitalization rate for participants retained in RC/AL facilities (12.6%) did not differ significantly from that of all nursing home participants (10.1%; p = .218). For the group transferred from residential care to nursing homes, however, the hospitalization rate was 29.2%, which differed significantly from both other groups (p < .001). Similarly, the residential care group retained in the facilities had similar rates of new or worsening morbidity (20.6%) to the nursing home cohort (23.2%; p = .280), whereas the rate for participants transferred to nursing homes (34.6%) differed significantly from both the retained RC/AL group (p < .001) and the nursing home group (p < .002). Baseline comorbidity was not associated with hospitalization among RC/AL participants with mild dementia or moderate to severe dementia.

Rates of Functional Change

The lower portion of Table 3 displays the rates of functional change over 1 year for all study participants, adjusted for baseline age, gender, race, education, marital status, length of stay on enrollment, cognitive status, and comorbidity. All participants were included, with change scores for discharged or deceased participants calculated on the basis of reported status immediately prior to discharge. Mean rates of decline in ADL, cognitive, and social function did not differ between the facilities and nursing homes for either the mild dementia cohort or the moderate to severe dementia cohort. Similarly, we noted no statistically significant difference in rates of change in behavior, depressive symptoms, or withdrawal.

Table 2. One-Year Disposition Outcomes of Residents With Dementia, by Dementia Severity and Facility Type, as Percent of Enrolled Participants

Disposition 1 Year After Study Entry	Mild Dementia		Moderate or Severe Dementia	
	RC/AL (*n* = 546)	NH (*n* = 243)	RC/AL (*n* = 227)	NH (*n* = 236)
Died, % (*N*)	11.7 (64)	17.7 (43)	22.0 (50)	27.5 (65)
Discharged to another setting, % (*N*)				
NH	22.2 (122)	7.0 (17)	25.1 (57)	7.6 (18)
RC/AL	6.6 (36)	2.5 (6)	6.2 (14)	0.4 (1)
Home	2.4 (13)	0.4 (1)	2.6 (6)	1.3 (3)
Remaining in facility, % (*N*)	52.2 (285)	71.2 (173)	38.3 (87)	62.7 (148)
Other (hospital or street), % (*N*)	1.1 (6)	0.4 (1)	2.6 (6)	0.4 (1)
Unknown, % (*N*)	3.7 (20)	1.2 (3)	3.1 (7)	0 (0)

Notes: RC/AL = residential care/assisted living; NH = nursing home.

Residence in Specialized Units

When we compared dementia special care units with nonspecialized settings, we observed few differences in outcomes (Table 4). In both RC/AL facilities and nursing homes, we noted no significant differences in mortality or in rates of change in cognition, behavioral problems, depression, social function, or withdrawal. Rates of hospitalization and of new or worsening morbidity were lower in nursing home special care units than in nonspecialized settings in nursing homes; however, we did not observe this relationship in RC/AL. ADL decline was more rapid in special care units than in nonspecialized settings in these facilities, largely as a result of an increased rate of decline among persons with moderate to severe dementia; however, we did not observe this association in nursing homes.

Discussion

The rapid growth of RC/AL in the United States has been accompanied by claims that this less medicalized form of long-term care can adequately serve many individuals traditionally housed in nursing homes. Because persons with dementia comprise the majority of nursing home residents and a growing proportion of RC/AL residents, an important question for policy makers, care providers, and families is whether or not assisted living can adequately serve some or all of the dementia residents who would otherwise be placed in nursing homes. The question has significant cost implications, because overall RC/AL costs may be significantly lower than those of nursing home care. According to Leon and Moyer (1999), if all dementia residents currently in nursing homes were shifted to residential care or assisted living, national long-term care expenditures would be reduced by 14%.

In this study we compared 12-month outcomes of a cohort of RC/AL residents with dementia with those of similar residents in nursing homes, controlling for baseline differences in subject age, gender, race, education, marital status, length of stay, cognition, and comorbidity. These analyses indicate that, for both mild and moderate to severe dementia, health outcomes did not differ between these facilities and nursing homes. Adjusted models (Table 3) identified no significant difference in mortality, incidence of new or worsening health conditions, or rate of change in functional dependency, cognition, behavioral problems, depressive symptoms, social function, or social withdrawal. Thus, these results suggest that, in terms of the health outcomes studied, many persons with dementia can be served equally well in either setting.

The one area where outcomes clearly differed was hospitalization rates, which were 69% and 42% higher, respectively, for participants with mild and moderate to severe dementia in RC/AL than for similar participants in nursing homes (Table 3). Although they did not appear to cause an overall increase in mortality or functional decline, such persons were largely responsible for the nearly 25% annual rate of nursing home transfer among facility residents (Table 2). This finding suggests that RC/AL facilities tend to have difficulty managing residents with dementia who have or develop significant medical or nursing care needs, in spite of some claims that these facilities can allow aging in place through the addition of home health, hospice, and other services (Thompson & Marinaccio, 1997). This finding is consistent with the results of Carter and Porell (2003), who reported that underlying respiratory, genitourinary, or circulatory conditions among nursing home residents were associated with increased risk of hospitalization. Thus, it appears likely that persons with dementia who are medically stable may do well over long periods of time in residential care or assisted living facilities. For those who are medically unstable, however, nursing homes may be better able to avoid hospitalization and, therefore, to both reduce cost and prevent the functional deterioration that frequently follows hospitalization (Coleman, Barbaccia, & Croughan-Minihane, 1990).

Table 3. One-Year Health and Health Care Utilization Outcomes of Participants With Dementia, by Dementia Severity and Facility Type

Health Outcomes During 1 Year	Mild Dementia			Moderate or Severe Dementia		
	RC/AL (n = 546)	NH (n = 243)	p	RC/AL (n = 227)	NH (n = 236)	p
Incidence rate per 100 participants per quarter						
Mortality[a]	3.2	4.2	.409	3.7	4.2	.683
Hospitalization[b]	14.2	8.4	.009	14.2	10.0	.115
New or worsening morbidity[b]	23.5	21.8	.574	21.1	21.7	.865
Mean change per 12 months[c]						
Increase in ADL dependency (MDS–ADL)	4.29	5.80	.059	0.87	1.13	.807
Increase in cognitive impairment (MDS–COGS)	0.41	0.71	.181	−0.13	0.45	.093
Increase in behavior problems (CMAI)	1.08	0.69	.604	1.72	1.49	.809
Increase in depressive symptoms (CSDD)	1.33	1.53	.753	1.52	0.85	.409
Decrease in social function	1.55	1.76	.568	0.91	1.44	.110
Increased withdrawal from activities (MOSES subscale)	2.84	2.24	.364	2.55	1.78	.307

Notes: RC/AL = residential care/assisted living; NH = nursing home; ADL = activity of daily living; MDS = Minimum Data Set; COGS = cognition; CMAI = Cohen-Mansfield Agitation Inventory; CSDD = Cornell Scale for Depression in Dementia; MOSES = Multidimensional Observation Scale for Elderly Subjects. All analyses were weighted, with RC/AL residents assigned weights based on probability of selection within each state. Nursing home participants were selected with equal probabilities of selection and therefore did not require weighting. All models were adjusted for baseline age, gender, race, education, marital status, length of stay, cognition (MDS-COGS), and number of comorbid conditions.

[a]Modeled using generalized estimating equations to fit a Poisson regression model; significance tests used Cox proportional hazards.

[b]Modeled using generalized estimating equations to fit a Poisson regression model.

[c]Modeled using generalized estimating equations to estimate differences in means, controlling for the baseline status of the variable being studied.

These analyses also found little difference in outcomes of dementia special care units when they were compared with nonspecialized settings (Table 4). In both nursing homes and RC/AL facilities, rates of mortality and of change in cognition, behavioral problems, depressive symptoms, social participation, and withdrawal did not differ between special care and nonspecial care units. Nursing home special care units did, however, appear to have reduced morbidity and hospitalization rates, and units in RC/AL to have higher rates of ADL decline. Although worthy of follow-up study, these isolated findings do not appear to represent a consistent pattern and, therefore, could well be spurious, considering the use of multiple comparisons in these analyses. Thus, the overall impression is that these findings add to a growing body of evidence that placement in a special care unit does not alter health and functional outcomes (Day, Carreon, & Stump, 2000; Phillips et al., 1997; Sloane, Lindeman, Phillips, Moritz, & Koch, 1995). Our study did not, however, evaluate psychosocial outcomes such as overall quality of life and resident and family satisfaction, and it is possible that these may have differed between special care units and nonspecialized settings.

Although we conducted the study and its analyses to minimize bias, several aspects of the study methods deserve comment. The selection of states and facilities, although designed to capture a wide range of facility types and residents, did result in a sample from which the unadjusted rates (Tables 1 and 2) cannot be generalized to either the study states or the nation. However, our outcome analyses (Tables 3 and 4) did adjust for sampling weights and, therefore, should be generalizable at least to the study states. The 41% facility refusal rated could constitute a source of bias; however, a survey of nonrespondent facilities identified few differences between responders and nonresponders (Zimmerman, Sloane, Eckert, Buie, et al., 2001). Because the outcome data were reported by facility staff, and licensed nurses are absent from some RC/AL settings, it is possible that reporting of certain health conditions differed across settings; however, the study used standardized instruments and measured outcomes, the majority of which do not require advanced medical training to recognize. Attrition of participants was common in both settings; however, we minimized the impact of attrition by gathering retrospective data on status just prior to discharge, including all observations, and weighting analyses per unit time that the participant resided in the facility. Finally, regarding the abundance of negative findings (i.e., differences not statistically significant at the 5% level) for the comparisons of outcomes between RC/AL facilities and nursing homes, as well as those between special care units and nonspecialized care settings, it is important to consider the magnitude of differences that could have been detected with reasonable power (i.e., at least 80%). Where the outcomes involved incidence

Table 4. One-Year Health and Health Care Utilization Outcomes of Participants With Dementia in Special Care Units Compared with Nonspecialized Units, by Facility Type

	RC/AL			NH		
Health Outcomes During 1 Year	SCU (n = 164)	Non-SCU (n = 607)	p	SCU (n = 94)	Non-SCU (n = 385)	p
Incidence rate per 100 participants per quarter						
Mortality[a]	7.0	4.0	.116	3.4	4.0	.540
Hospitalization[b]	17.3	14.4	.430	3.9	9.6	.006
New or worsening morbidity[b]	26.7	25.3	.772	15.0	22.0	.043
Mean change per 12 months[c]						
Increase in ADL dependency (MDS–ADL)	5.64	2.91	.029	3.00	3.19	.886
Increase in cognitive impairment (MDS-COGS)	0. 33	0. 30	.943	0. 58	0.61	.903
Increase in behavior problems (CMAI)	−1.53	−1.14	.763	−2.18	− 0.72	.168
Increase in depressive symptoms (CSDD)	1.59	1.32	.823	0.89	1.25	.630
Decrease in social function	1.58	1.34	.681	1.88	1.46	.303
Increased withdrawal from activities (MOSES subscale)	3.48	2.58	.409	2.22	1.77	.604

Notes: RC/AL = residential care/assisted living; NH = nursing home; ADL = activity of daily living; MDS = Minimum Data Set; COGS = cognition; CMAI = Cohen-Mansfield Agitation Inventory; CSDD = Cornell Scale for Depression in Dementia; MOSES = Multidimensional Observation Scale for Elderly Subjects. All analyses were weighted, with RC/AL participants assigned weights based on probability of selection within each state. Nursing home participants were selected with equal probabilities of selection and therefore did not require weighting. All models were adjusted for baseline age, gender, race, education, marital status, length of stay, cognition (MDS-COGS), and number of comorbid conditions.
[a]Modeled using generalized estimating equations to fit a Poisson regression model; significance tests using Cox proportional hazards.
[b]Modeled using generalized estimating equations to fit a Poisson regression model.
[c]Modeled using generalized estimating equations to estimate differences in means, controlling for the baseline status of the variable being studied.

rates of death, hospitalization, and morbidity, the detectable differences were in the range of 5 to 15 events per 100 residents per quarter. Where the outcomes involved changes in physical, cognitive, and behavioral function, the detectable differences were in the range of 0.5 to 2 points on the various scales of measurement used, corresponding to standardized effect sizes in the range of 0.2 to 0.3. It therefore appears that the study was of sufficient size to detect outcome differences that are regarded to be relatively small in magnitude (Cohen, 1977).

In evaluating the difference between RC/AL and nursing home care, a key question is the extent to which health outcomes of chronic, progressive conditions such as Alzheimer's disease can be modified by the care setting. These analyses add additional weight to findings from other studies, which suggest that physiological factors have a far greater influence on health outcomes of long-term care populations than the care they receive, and that the influence of care settings on health and functioning is relatively minor. At the same time, they suggest that some facility types may be better able to reduce hospital use, thereby affecting overall care costs and limiting the need for residents and families to contend with transitions to another care setting.

Individual resident factors such as general physical health have successfully been used to create mortality risk indices that predict outcomes across facilities (Carlson et al., 2001). Studies also have shown that resident baseline characteristics significantly predict resident outcomes such as cognitive functioning, agitation, and social or language skills after 1 year (Chappell & Reid, 2000). In contrast, facility characteristics appear to have a minimal impact on such outcomes (Chafetz, 1991; Holmes et al., 1990; Webber, Breuer, & Lindeman, 1995). Thus, it appears that, although facility type and design may be important for resident and family satisfaction, their impact on resident outcomes such as mortality, morbidity, and functional status is relatively minor. Such findings reinforce the current trend to focus more on quality of life and less on health outcomes in evaluating quality of care.

Finally, it should be kept in mind that RC/AL facilities, although quite heterogeneous, are generally designed to serve a population that on average is less impaired than nursing home residents (Zimmerman et al., 2003). The data presented in this article document a high morbidity burden among the growing population of RC/AL residents with dementia. Given the high risk of hospitalization, transfer to nursing homes, and mortality demonstrated in these analyses, and the relative lack of research to date, the RC/AL setting may present promising opportunities for the development of interventions that could reduce future disability, morbidity, and mortality in a population that is still quite functional but at high risk for decline. One component of such interventions would have to be better methods for the

prospective identification of individuals who are likely to become medically unstable, thereby improving the efficiency of placement of individuals with dementia in more or less medicalized settings.

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Dementia Care and Quality of Life in Assisted Living and Nursing Homes

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Purpose: There are few empirical studies relating components of long-term care to quality of life for residents with dementia. This study relates elements of dementia care in residential care/assisted living (RC/AL) facilities and nursing homes to resident quality of life and considers the guidance this information provides for practice and policy. **Design and Methods:** We used a variety of report and observational measures of the structure and process of care and 11 standardized measures of quality of life to evaluate the care for and quality of life of 421 residents with dementia in 35 RC/AL facilities and 10 nursing homes in four states. Data were collected cross sectionally on-site, and we conducted a 6-month follow-up by telephone. **Results:** Change in quality of life was better in facilities that used a specialized worker approach, trained more staff in more domains central to dementia care, and encouraged activity participation. Residents perceived their quality of life as better when staff was more involved in care planning and when staff attitudes were more favorable. Better resident–staff communication was related to higher quality of life as observed and reported by care providers. Also, more stable resident–staff assignment was related to care providers' lower quality-of-life ratings. **Implications:** Improvement in resident quality of life may be achieved by improved training and deployment of staff.

Key Words: Long-term care, Residential care, Staff practices, Training, Observation

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Between 23% and 42% of residents in residential care/assisted living (RC/AL) settings have moderate or severe cognitive impairment, as do more than one half of nursing home residents (Zimmerman et al., 2003). While attention has been focused on the quality of long-term care for decades, remarkably little has focused on how care in both of these settings relates to quality of life for persons with dementia—in part because dementia-focused quality-of-life measures are comparatively new, and in part because RC/AL as a site of long-term care has only recently come under study (Ready & Ott, 2003; Wunderlich & Kohler, 2001). Such information is critically needed to guide policy and the development of best practices.

This article focuses on care and quality-of-life issues that have practice and policy relevance. It characterizes the current state of dementia care in RC/AL and nursing homes (based on report and observation); describes the characteristics and quality of life of residents with dementia in RC/AL and nursing homes (examining quality of life both cross sectionally and longitudinally, using multiple quality-of-life measures from the perspectives of residents and staff, and from observation); determines how dementia care (including special care units for residents with dementia) relates to resident quality

of life; and considers the guidance this information provides for practice and policy.

Design and Methods

Sample and Recruitment

The Dementia Care project recruited individuals with a diagnosis of dementia living in a diverse set of facilities in four states that have different yet well-developed RC/AL industries (Florida, Maryland, New Jersey, and North Carolina). RC/AL included those facilities licensed by states at a nonnursing home level of care that provide room and board; assistance with activities of daily living (ADLs), personal care, and medication administration; and 24-hour oversight. Using the typology developed for the Collaborative Studies of Long-Term Care (CS-LTC), the study stratified RC/AL facilities to include: (a) facilities with < 16 beds; (b) facilities with ≥ 16 beds of the "new-model" type (those proliferating under the recent surge of assisted living that provide nursing care and cater to an impaired population); and (c) "traditional" facilities with ≥ 16 beds, not meeting new-model criteria. Details of the CS-LTC and the facility typology can be found elsewhere (Zimmerman et al., 2001).

The Dementia Care project enrolled a purposive sample of 45 facilities. For efficiency, facilities with fewer than 2 eligible residents (in smaller facilities) or 13 eligible residents (in other facilities) were excluded from study. Facilities were enrolled in a manner that maintained stratification across states and by facility type and that maximized the number of residents from smaller facilities. Twenty-two facilities (33%) declined to participate. These facilities did not differ from participating facilities in reference to type, size, or state. The final sample included 14 (31%) RC/AL facilities with < 16 beds; 11 (24%) traditional facilities; 10 (22%) new-model facilities; and 10 (22%) nursing homes. Twelve facilities were from North Carolina, and all other study states had 11 facilities. Given the purposive nature of facility selection, the descriptive data presented in this study are best used to formulate hypotheses.

Residents were randomly selected in each facility from among those aged 65 years or older who had a diagnosis of dementia. They were ineligible if they had a primary diagnosis of Huntington's disease, alcohol-related dementia, schizophrenia, manic-depressive disorder, or mental retardation. To provide similar representation across facility types, a maximum of 4 residents per smaller facility and 19 per larger facility were enrolled. A total of 575 eligible residents or their families were approached for consent. Of these, 421 (73%) agreed to participate, 66 (11%) declined, and 88 (15%) were unable to provide consent and had family who were unreachable. Additional information about the design is

provided in the introduction to this issue (Zimmerman, Sloane, Heck, Maslow, & Schulz, 2005).

Data Collection

Data collection was conducted between September 2001 and February 2003. Data collectors observed the physical environment of all facilities and characteristics of a random sample of participating residents in each facility (79%) and conducted interviews with each resident participant (95% response rate), his or her most involved family member (84% response rate), the direct care provider who knew the resident best (98% response rate), the supervisor (position above a direct care provider) who knew the most about the resident (89% response rate), and the facility administrator (to obtain facility-level data; 100% response rate). In 4% of cases—usually in smaller facilities—the direct care provider and supervisor were the same individual. Ninety-four percent of direct care providers were nurse or personal care aides, and 78% of supervisors were registered nurses (RNs) or licensed practical nurses (LPNs).

Measures

Data were collected to assess care provision (facility-level and resident-level) and resident quality of life.

Facility-Level Care Provision.—Dementia care measured at the facility level applied to all participants within a facility (or unit, if the facility included both an area designated for dementia care and an area not so designated). Administrators provided information about facility demographics (facility type, age, profit status, affiliation with another level of care or a chain of facilities, number of beds, presence of dementia-specific unit) and case-mix related to dementia diagnosis and each of six ADL impairments (eating, dressing, walking, transferring, bathing, and continence). The administrator also reported on several aspects of staffing, including the stability of care provider–resident assignments, whether the facility provided care based on a universal worker perspective (where staff fill multiple roles) and/or a specialized worker perspective (where staff have specialized roles), the number of nurses and nursing or personal care aides (overall and contract), staff turnover (at the administrator, nursing, and aide level), and the extent to which the facility sought to hire workers with experience in dementia care. Four measures of facility policies and practices were obtained, based on the Policy and Program Information Form (POLIF; Moos & Lemke, 1996): policy choice (7 items), leniency of admissions (24) and discharge policies (24), and acceptance of problem behavior (16). The latter three measures

were assessed separately for dementia-specific and non-dementia-specific areas when applicable, and all were scored from 0 to 100, reflecting the percentage of items endorsed. Involvement in formal care planning of professional staff (averaged across administrator, physician, nurse, activity specialist, social service worker, mental health specialist, clergy, and dietician) and aides was scored from never to weekly.

Facility-level items regarding formal staff training, resident assessment, and treatment practices were ascertained for each of the following six domains of care: depression, pain, behavioral symptoms, ambulation, nutrition, and hydration. (The brief reports included in this issue further detail these measures.) Reports of the proportion of supervisory and direct care staff who received formal training in each domain within the past year were categorized as 0 (none), 1 (some; 1–74%), or 2 (most; $\geq$ 75%); scores were then summed across the six domains to yield a 0 through 12 summary score. Similarly, an assessment variable was created, consisting of the sum of domains for which the facility used professional assessment (e.g., mental health professionals for depression) and written, standardized assessment. A professional treatment variable was created as the average across the six areas of the percent of residents receiving ongoing, professional treatment for impairment in that area; "other/ informal treatment" was created to be the number of areas for which the facility used other treatments; and perceived treatment success was the number of areas in which the administrator felt the facility did "quite a bit" or "extremely well" treating their residents. Except for perceived success, assessment and treatment were obtained separately for dementia-specific and non-dementia-specific areas. Three additional measures of treatment included the proportion of study participants who had received an antipsychotic or sedative hypnotic medication at least 4 out of the last 7 days (reported by the supervisor), the extent to which the facility provided and encouraged activity participation in 10 domains, separately by care area (e.g., exercise, personal care, social, meal preparation, work-oriented; Zgola, 1987), and the use of stimuli in seven areas (e.g., craft or household items).

Finally, data collectors systematically observed the environment, using the Therapeutic Environment Screening Survey for RC/AL (TESS–RC/AL), a measure derived from the Therapeutic Environment Screening Survey for Nursing Homes (TESS-NH; Sloane et al., 2002). Observations were used to compute two scales (separately for dementia-specific and non-dementia-specific areas): the Special Care Unit–Environmental Quality Score (SCU-EQS), which ranges from 0 to 38 and assesses 18 components relevant for individuals with dementia (e.g., orientation and memory cues); and the Assisted Living–Environmental Quality Score (AL-EQS), which ranges from 0 to 30 and assesses 15 components (some of which are in the SCU-EQS) more characteristic of assisted living environments (e.g., resident autonomy and homelikeness).

Resident-Level Care Provision.—Dementia care measured at the resident level referred specifically to the study participants or their staff care providers, using data from interviews with staff and family members, and direct observation. The supervisor reported whether the resident had received cholinesterase inhibitors at least 4 of the past 7 days. Direct care providers reported their approaches to dementia care, their work satisfaction, and their work stress. The Approaches to Dementia measure was used to assess staff attitudes; it contains 19 items, summed to form a total score as well as person-centered and hope subscores (Lintern, Woods, & Phair, 2000b). The Work Stress Inventory was used to assess the frequency of 45 staff stressors related to work events, resident care, relationships with coworkers and supervisors, workload and scheduling, and physical design (Schaefer & Moos, 1993). Work satisfaction was measured using the 21-item Staff Experience Working with Demented Residents measure, which assesses satisfaction of one's own expectations, coworkers and supervisors, work environment, and resident care (Åström, Nilsson, Norberg, Sandman, & Winblad, 1991). These measures are described in detail elsewhere in this issue (Zimmerman, Williams, et al., 2005). In addition, family members reported the amount of time they spent each week visiting or talking on the phone with the resident.

Direct observations of study residents were conducted at 5-min intervals during three 1-hr observation periods (chosen to exclude mealtimes), from which four measures of resident care were derived. Communication was measured as the percent of observations during which the resident received any verbal communication from a staff member, physical contact was the percent of observations during which the resident had any physical contact with another person, and personal detractors and positive person work were similarly measured as the percent of observations in which any personal detractors (staff behaviors that demean or depersonalize) or positive person work (positive interactions between staff and resident) were noted (Bradford Dementia Group, 1997). Whether the resident was ever observed in restraints (full or partial bedrails, trunk, wrist, ankle, or chair restraints) also was noted, and during the first observation each hour, residents were assessed to determine if they appeared ungroomed, unkempt, or unclean and whether appearance was ever inappropriate with respect to time of day, season, or place.

Resident Characteristics.—The supervisor provided information on several resident characteristics, including demographics (age, gender, race, marital status) and length of stay. The presence of behavioral

symptoms of dementia during the past 2 weeks was measured using the Cohen-Mansfield Agitation Inventory (CMAI; Cohen-Mansfield, 1986), functional status was measured as the number of activities in which the resident needed supervision or assistance using the seven items from the Minimum Data Set Activities of Daily Living (MDS-ADL) scale (Morris, Fries, & Morris, 1999), residents were classified as being depressed if they scored ≥ 7 on the Cornell Scale for Depression in Dementia (CSDD; Alexopoulos, Abrams, Young, & Shamoian, 1988), and comorbidity was the number of chronic conditions (out of 11) reported by the supervisor. Finally, cognitive deficit was categorized based on the Mini-Mental State Exam (MMSE; Folstein, Folstein, & McHugh, 1975) score administered to the resident, or (if the MMSE was not available) the Minimum Data Set–Cognition Scale (MDS-COGS; Hartmaier, Sloane, Guess, & Koch, 1994) reported by the supervisor. Cognition was scored as follows: mild (MMSE 17–30 or MDS-COGS 0–1), moderate (MMSE 10–16 or MDS-COGS 2–4), severe (MMSE 3–9 or MDS-COGS 5–6), or very severe (MMSE 0–2 or MDS-COGS 7–10).

Quality of Life.—Quality of life was assessed by the resident (three measures), direct care provider (six measures, one of which was longitudinal), and through observation (three measures); measures are described in detail elsewhere (Sloane et al., 2005, this issue). Unless otherwise noted, higher scores indicate better quality of life. Residents with a MMSE of 10 or greater completed the Dementia Quality of Life (DQOL; Brod, Stewart, Sands, & Walton, 1999), the Quality of Life in Alzheimer's Disease Activity measure (QOL in AD–Activity; Albert et al., 1996), and the Quality of Life–Alzheimer's Disease (QOL-AD; Logsdon, Gibbons, McCurry, & Teri, 2000), as modified by Edelman, Fulton, Kuhn, and Change (2005, this issue) for use in long-term care settings.

Care providers completed proxy versions of the QOL in AD–Activity, and the QOL-AD, as well as the positive and negative affect portions of the QOL in AD (higher negative affect scores indicate poorer quality of life), and the Alzheimer Disease Related Quality of Life (ADRQL; Rabins, Kasper, Kleinman, Black, & Patrick, 2000). Additionally, the proxy version of the QOL-AD was readministered 6 months after initial data collection. We computed raw change as the difference between baseline and 6 months, with positive scores indicating improvement in quality of life; to account for regression to the mean, we estimated adjusted change as the residual from regression of raw change on the baseline value, which therefore has a sample mean of exactly zero (Cronbach & Furby, 1970). Because change is influenced by baseline status, we based all statistical comparisons on adjusted values.

Using the observational procedures described above, we recorded behaviors in accordance with the Dementia Care Mapping (DCM) protocol (Bradford Dementia Group, 1997) and a modification of the Philadelphia Geriatric Center Affect Rating Scale (PGC-ARS; Lawton, Van Haitsma, & Klapper, 1996). DCM-derived measures included the percent of observations with a Type I Behavior Category Code (DCM % BCC Type I), considered to be "good" behaviors such as conversation or creative expression, and the mean Well- and Ill-Being (WIB) score, with anchors of +5 and −5, indicating the state of well-being. (See Brooker, 2005, and Sloane et al., 2005, this issue, for a more in-depth discussion). The PGC-ARS was coded to record the predominant emotion at each observation (scored from 0 for anxiety, fear, or sadness, to 3 for high pleasure) and summarized at the resident level as the percent of the highest possible score.

Analyses

We used simple descriptive methods (means and standard deviations for continuous measures, percentages for categorical measures) to describe the components of dementia care. For measures assessed separately in dementia-specific and non-dementia-specific care areas, comparisons used generalized estimating equations (GEE: Diggle, Heagerty, Liang, & Zeger, 2002) applied to linear (continuous) or logistic (dichotomous) models, specifying an exchangeable correlation matrix to account for resident clustering within facility.

We estimated means and standard errors of the quality-of-life measures according to facility type and resident characteristics, dichotomized at the sample median or at commonly accepted cutpoints; we adjusted the standard errors for clustering using Taylor series expansion methods (Woodruff, 1971). We tested the statistical significance of these associations using linear mixed models with random effects specified as follows: for care provider reported quality-of-life measures, models included random effects for facility and care provider (nested within facility); for resident-reported measures, models include a random effect for facility; and for directly observed measures, models include random effects for facility and observer.

We estimated the association between care and quality of life using partial Pearson correlation coefficients, adjusting for facility type; resident age, gender, race, marital status, length of stay; and cognitive, ADL, number of comorbid conditions, depressive, and behavioral symptoms. To maximize the sample size for resident-reported quality-of-life analyses in the presence of covariate missingness, we did not adjust associations for age, race, marital status, or length of stay (none of which was significantly related to quality of life). We tested the statistical significance of these associations using linear mixed models, controlling for these

resident characteristics and with random effects as specified above.

Results

The mean values shown in Table 1 indicate that, on average, almost one third of beds were dementia specific, and slightly more than one half of the facility residents were reported to have dementia or at least one ADL impairment. In the average facility, staff tended to be reassigned to new residents monthly or less frequently, and 58% and 38% of facilities used a universal worker and specialized worker philosophy, respectively. Approximately 11% of nursing care and 2% of personal care was provided by contract workers, with 46% of nurses turning over annually. Care planning practices included the involvement of professional staff and aides 1 to 3 times a month. On average, less than 75% of staff were trained in the six care areas (the figure corresponding to a score of 8), but facilities provided professional assessment in more than five of the areas and written or standardized assessment in approximately three. Almost one third of residents were reported to have received professional care in the six care areas, with the administrator perceiving success in five areas. In the average facility, nearly one half (48%) of study residents were taking antipsychotic or sedative hypnotic drugs.

Variables for which two figures are provided refer to dementia specific versus non-dementia-specific care areas. While the environmental AL-EQS was scored statistically significantly higher in non-dementia-specific areas (13.4 vs 11.9), dementia-specific areas were more accepting of problem behaviors (23% vs 13%) and encouraged activities slightly more frequently (score 2.4 vs 2.2; all $p < .05$).

Table 2 separates care by dementia-specific area for all resident-level variables. It shows that supervisors (of the residents enrolled in this study) who worked in non-dementia-specific areas had slightly more experience but that positive person work and physical contact were witnessed more often in dementia-specific areas (22% vs 17%, and 9% vs 6% of observations, respectively). Overall, 13% and 20% of resident participants were in restraints and ungroomed during at least one observation, and 29% were taking a cholinesterase inhibitor. On average, families spent almost 7 hr per week visiting or talking with the resident.

As rated by care providers and observation (in unadjusted analyses), quality of life was related to facility type (see Table 3). Care providers in RC/AL rated quality of life higher than those in nursing homes using three different measures (ADRQL, QOL in AD–positive affect, QOL-AD); two measures did not differentiate facility type (QOL in AD–activity, QOL in AD–negative affect), nor did change in quality of life. The remainder of Table 3 provides the distributions of quality of life by resident characteristics. Change in quality of life (9th and 10th QOL columns) was related only to level of cognitive impairment (more impaired residents had greater reductions in QOL-AD compared to less impaired residents; raw change of −2.6 vs −2.1, $p < .01$) and depression (depressed individuals had greater reductions in QOL-AD compared to the nondepressed; change of −2.7 vs −2.2, $p < .05$). Cross sectionally, based on resident report, only fewer comorbidities were related to better quality of life. Based on care provider report and observation, less cognitive and functional impairment and no behavioral symptoms or depression were associated with better quality of life.

Tables 4 and 5 indicate statistically significant covariate adjusted associations between facility-level (Table 4) and resident-level (Table 5) components of care and quality of life. Looking first at change in quality of life over 6 months, adjusted quality of life was better (declined less) in facilities with specialized workers, with more staff training in more areas (supervisor and direct care staff), and that encouraged activity participation more frequently (all $p < .05$). No resident-level components of care were associated with change in quality of life at this statistical level, nor were the many other facility-level components under study.

Further, while facility type and many other facility characteristics were not significantly related to cross-sectional quality of life in adjusted analyses (facility size, age, affiliation, percent dementia beds, and dementia and ADL impairment case-mix), a better environment was related to worse quality of life reported by care providers (QOL in AD–negative affect, and QOL-AD) but better observed quality of life on the DCM BCC Type I codes (SCU-EQS $p < .05$ for all). Similarly, while many staff variables were not significantly related to quality of life (universal worker, RN, LPN, and aide FTEs; administrator and aide turnover; and extent hire for experience), more stability in staff-resident assignment was related to worse quality of life as reported by the care provider. Larger numbers of contract workers on staff were related to better quality of life as reported by residents and care providers, and higher RN and LPN turnover was related to worse quality of life on the observation of DCM well-being.

The remaining rows on Table 4 indicate the diversity with which policies and practices relate to quality of life. While virtually all policies and practices under study related to quality of life, they did so inconsistently across different measures. For example, having more flexible admission, discharge, and acceptance of problem behavior policies related positively to care provider report of QOL in AD–positive affect, and involving professional staff in care planning related positively to resident reported QOL-AD and observed affect (PGC-ARS). The

Table 1. Distribution of Facility-Level Components of Dementia Care in the Study Sample

Facility-Level Characteristic[a]	M (SD) or %[b]
Demographics	
Type	
RC/AL	
< 16 bed	31.1%
Traditional	24.4%
New-model	22.2%
Nursing home	22.2%
Size (no. of beds)	61.8 (52.2)
Age (years)	19.8 (20.7)
For profit	75.6%
Affiliated	22.2%
Chain	44.4%
Dementia-specific beds (%)	29.9 (40.4)
Case-mix (all facility residents)	
Percent with dementia	55.7 (24.4)
Average percent with ADL impairment (of 6)[c]	56.5 (24.1)
Physical environment (observed)[c]	
SCU-EQS (0–38)	23.6 (5.6); 25.2 (5.2)
AL-EQS (0–30)	11.9 (4.0); 13.4 (4.3)*
Staffing	
Stability of staff-resident assignment (0–5)[c]	3.6 (1.8); 3.1 (1.8)
Universal worker philosophy	58.3%; 58.8%
Specialized worker philosophy	37.5%; 38.2%
Nursing (FTE, RN or LPN, per 10 residents)	1.2 (1.3)
Aide (FTE per 10 residents)	4.1 (2.2)
Extent hire for experience (1–5)[c]	3.0 (1.1)
Contract workers	
Percent of nursing (RN, LPN) by contract workers	11.3 (24.5)
Percent of personal care by contract workers	2.1 (6.5)
Annual turnover (%)	
Administrator	9.3 (34.4)
RN and LPN	46.4 (59.9)
Nurse aide	72.1 (92.3)
Policies and Practices	
Permissive admission policies (of 24, %)	88.3 (9.2); 83.9 (11.5)
Permissive discharge policies (of 24, %)	89.1 (7.8); 86.8 (9.6)
Acceptance of problem behaviors (of 16, %)	23.1 (15.6); 13.1 (11.5)*
Policy choice (of 7, %)	56.5 (28.5)
Care planning[c]	
Professional staff involvement (0–3)	2.1 (1.1)
Aide involvement (0–3)	1.9 (1.2)
Formal training, last year (in 6 areas)[c]	
Supervisors (0–12)	8.3 (4.0)
Direct care staff (0–12)	8.0 (3.9)
Assessment[c]	
Professional (of 6 areas)	5.5 (0.8); 5.3 (1.4)
Written, standardized (of 6 areas)	3.0 (2.0); 2.7 (2.2)
Treatment	
Professional (average percent across 6 areas)[c]	30.3 (16.7); 28.0 (14.3)
Other or informal (of 6 areas)[c]	4.6 (1.7); 4.7 (1.7)
Perceived success (of 6 areas)[c]	4.9 (1.4)

Table 1. (Continued)

Facility-Level Characteristic[a]	M (SD) or %[b]
Percent on antipsychotic or sedative hypnotic	47.7 (27.6)
Encouragement of activities (0–4)[c]	2.4 (0.7); 2.2 (0.5)*
Use of stimuli by residents with dementia (0–4)[c]	2.1 (0.8)

Notes: RC/AL = residential care/assisted living; ADL = activity of daily living; SCU-EQS = Special Care Unit–Environmental Quality Scale; AL-EQS = Assisted Living–Environmental Quality Scale; RN = registered nurse; LPN = licensed practical nurse. For the table, N = 45 facilities.

[a]All data are from administrator interview, except physical environment (which was based on direct observation) and medication use (which was aggregated from supervisor reports of residents enrolled in this study). The sample size for facilities varied from 41–45 because of missing data.

[b]Characteristics with two values shown were measured separately for dementia-specific and non-dementia-specific care areas within facilities. The first value is for the dementia-specific portion (n = 24); the second is for the non-dementia-specific portion (n = 35). Ten facilities were entirely dementia specific, 14 were partially dementia specific, and the remaining 21 had no area designated for dementia-specific care.

[c]ADLs include eating, dressing, walking, transferring, bathing, and continence; SCU-EQS and AL-EQS are explained in the text; staffing stability was scored from 0 = changes more than once a week to 5 = never changes (average between 3 and 4 indicates changes between monthly and less than once a month); extent hire for experience is the extent to which the facility tries to hire workers with training and/or experience in dementia care, scored from 1 = not at all to 5 = extremely (3 corresponds to moderately); policies are explained in the text; care planning is frequency of involvement in formal care plan meetings, scored from 0 = never to 3 = weekly and (for professional staff) was averaged across eight types of staff (2 corresponds to 1–3 times a month); formal training is a summary score for the proportion of supervisory and direct care staff with formal training in detection and treatment of problems in each of six care areas (pain, depression, ambulation, eating, drinking, behavioral symptoms), scored as 0 = none, 1 = 1–74%, 2 = 75% or more; assessment is the number of six care areas in which the facility or unit uses professional assessment by medical personnel or written, standardized assessment; professional treatment is the average percent of residents who received ongoing professional treatment for problems in each of the six care areas during the past year; other, informal treatment is the number of six care areas in which the facility uses such treatment; perceived success is the number of these six care areas for which the administrator felt the facility was "quite a bit" or "extremely" successful in treating residents; encouragement of activities is for 10 activities, and was the average frequency (scored as 0 = never to 4 = several times a day) that the activity was provided and resident participation encouraged (2 corresponds to between one and 6 days per week); and use of stimuli is for seven types of stimuli, and was the average frequency (scored as 0 = never to 4 = several times a day) that the stimuli were available and used by at least 1 resident with dementia (2 corresponds to between 1 and 6 days per week).

*p < .05 for difference between dementia-specific care area and non-dementia-specific care area, based on resident-level analysis in which residents are assigned a value based on area of residence, using GEE applied to linear or logistic regression for continuous and dichotomous characteristics, respectively, to account for clustering within facilities.

strongest association for resident-reported quality of life was witnessed for facility use of antipsychotic and sedative hypnotic medications (negatively associated with QOL-AD, $p < .01$). The one facility-level

Resident-Level Characteristic[a]	M (SD) or %		
	Overall (N = 421)	In Dementia Specific Care Area or Facility (N = 170)	In Nondementia Specific Care Area or Facility (N = 239)
Reported and observed care (%)			
Use of cholinesterase inhibitor	29.2	35.3	26.0
Observation (ever observed)			
In restraints	13.2	12.4	12.8
Ungroomed appearance	19.8	18.8	19.8
Unsuitable appearance	7.6	6.3	7.9
Staff experience, perceptions and observed behaviors			
Experience in current position[b]			
Supervisor (1–5)	4.3 (1.0)	4.1 (1.0)	4.5 (0.9)*
Direct care provider (1–5)	4.4 (0.9)	4.4 (0.9)	4.3 (1.0)
Perceptions of direct care provider[b]			
Approaches to care, total (19–95)	71.1 (7.0)	71.9 (6.5)	70.7 (7.3)
Hope (8–40)	24.2 (4.5)	24.3 (4.5)	24.2 (4.7)
Person-centered (11–55)	46.9 (4.2)	47.6 (4.4)	46.4 (4.1)
Work stress (1–5)	1.8 (0.5)	1.8 (0.6)	1.8 (0.5)
Work satisfaction (0–84)	62.2 (10.3)	62.7 (9.8)	62.1 (10.7)
Observation (0–100%)[c]			
Percent, communication	19.7 (18.3)	21.9 (17.3)	18.0 (19.1)
Percent, personal detractors	3.4 (6.5)	3.2 (4.8)	3.6 (7.8)
Percent, positive person work	19.2 (16.3)	22.0 (15.4)	17.2 (16.9)*
Percent, physical contact	7.6 (9.0)	9.2 (9.1)	6.2 (8.8)*
Family involvement (hr/week)	6.8 (7.2)	6.2 (6.7)	7.3 (7.5)

Notes: For the table, N = 421 residents.

[a]Data are from supervisor, direct care provider, and family interview, or direct observation (36 observations, conducted every 5 minutes over three nonmealtime hours for restraint use, communication, personal detractors, positive person work, and physical contact; and on three observations conducted during the first 5 minutes of each hour for appearance). Direct observations were completed for 333 residents (138 in dementia-specific care areas or facilities and 187 in non-dementia-specific care areas or facilities). For measures derived from interviews, the sample size varies from 343–379 for the overall sample, from 129 to 154 for residents of dementia-specific care areas or facilities, and from 196 to 228 for residents of non-dementia-specific care areas or facilities, because of missing data. Location of residence (special care area vs not) was unknown for 12 residents of one facility; these residents were included in the overall estimates but excluded from the area-specific estimates.

[b]Experience was scored as: 1 = < 1 month; 2 = 1–5 months; 3 = 6–11 months; 4 = 1–2 years; 5 = > 2 years. Approaches to care (Lintern, Woods, & Phair, 2000a, 2000b) was based on the sum of responses to 19 items (each scored from 1 = strongly agree to 5 = strongly disagree) regarding approaches to dementia and attitudes towards individuals with dementia; the hope subscale included 8 items, and the person-centered subscale included 11 items, with higher scores indicating more positive attitudes. Work stress was the Work Stress Inventory (Schaefer & Moos, 1993), the average of the frequency (each scored 1 = never to 5 = often) for 45 work stressors, with higher scores indicating greater stress. Work satisfaction was the Experience of Work with Demented Residents measure (Åström et al., 1991) and was the sum of 21 items, each scored 0 = not at all to 4 = extremely, with higher scores indicating greater satisfaction.

[c]Each of the observational items was the percent of observations (out of up to 36 per resident) during which the item was observed. Communication refers to communication from staff. Personal detractors and positive person work are explained in the text. Physical contact refers to observed contact with staff or other residents.

*$p < .05$ for difference between dementia-specific care area and non-dementia-specific care area, based on resident-level analysis in which residents were assigned a value based on area of residence, using GEE applied to linear or logistic regression for continuous and dichotomous characteristics, respectively, to account for clustering within facilities.

component of care that related to quality of life as assessed by residents, care providers, and observation was the provision of professional treatment for the six care areas under study; it was negatively related to quality of life as reported by residents (DQOL) and observed (DCM BCC Type I codes), but positively related to care provider reports (QOL in AD–positive affect).

In addition, one component of resident-level care related to quality of life across all three sources (see Table 5). Residents who were observed to be ungroomed reported their own quality of life to be worse (QOL-AD), as did care providers (QOL in AD–activity) and observation (DCM BCC Type I codes). Residents who had staff who espoused more dementia-sensitive attitudes (especially hope) rated their quality of life higher on two measures (DQOL and QOL in AD–activity). Observed interactional style (more communication, positive person work, and physical contact, fewer personal detractors) was

Table 3. Distribution of Quality of Life Score, by Facility Type and Resident Characteristics

Characteristic	N	Resident Report[a]			Direct Care Provider Report[a]								Observation[a]	
		DQOL (n = 100)	QOL in AD–Activity (n = 110)	QOL-AD (n = 120)	ADRQL (n = 410)	QOL in AD–Activity (n = 400)	QOL in AD–Positive Affect (n = 403)	QOL in AD–Negative Affect (n = 383)	QOL-AD (n = 410)	QOL-AD, Raw Change[a] (n = 402)	QOL-AD, Adjusted Change (n = 402)	PGC-ARS (n = 333)	DCM, % BCC Type I (n = 333)	DCM, WIB (n = 333)
Overall	421	17.5 (0.4)	9.5 (0.6)	42.8 (1.0)	75.2 (0.9)	9.3 (0.4)	11.9 (0.2)	6.7 (0.2)	36.9 (0.5)	−2.4 (0.5)***	0.00 (0.47)	33.6 (0.5)	35.4 (1.9)	.74 (.04)
Facility type														
Nursing home (reference)	137	18.3 (0.7)	10.1 (1.2)	42.1 (1.0)	71.3 (1.8)	8.3 (0.5)	11.0 (0.3)	7.2 (0.4)	34.6 (1.0)	−1.8 (0.7)	−0.18 (0.73)	32.0 (0.8)	29.1 (3.2)	.54 (.07)
< 16 beds	48	16.0 (1.3)†	7.2 (1.2)	39.0 (3.2)	76.6 (2.5)†	9.3 (1.1)	11.8 (0.6)	6.2 (0.5)	37.7 (1.3)†	−2.2 (1.1)	0.54 (1.12)	32.9 (0.6)	45.2 (5.0)*	.80 (.06)*
Traditional	101	17.7 (0.5)	9.8 (1.0)	44.7 (1.4)	79.9 (1.8)**	9.9 (0.8)	12.7 (0.3)**	6.3 (0.4)	38.9 (1.0)**	−2.7 (1.3)	0.48 (1.07)	34.6 (1.1)*	40.9 (4.9)†	.90 (.06)***
New-model	135	17.3 (0.7)	9.8 (1.4)	42.8 (1.7)	75.2 (1.2)†	10.0 (0.7)	12.1 (0.3)†	6.5 (0.3)	37.6 (0.9)†	−3.0 (0.9)	−0.38 (0.91)	35.0 (0.8)*	33.9 (2.7)	.81 (.06)**
Length of stay														
< 12 months	94	17.2 (0.6)	9.8 (0.8)	42.3 (1.3)	78.5 (2.2)†	10.3 (0.7)*	12.0 (0.3)	6.4 (0.4)	39.4 (1.1)***	−3.7 (1.0)	−0.39 (0.86)	34.7 (1.1)	38.7 (3.7)	.84 (.06)†
≥ 1 year	276	17.4 (0.6)	9.1 (0.9)	42.3 (1.4)	73.8 (1.1)	9.1 (0.4)	11.8 (0.2)	6.7 (0.2)	36.1 (0.6)	−2.0 (0.6)	0.03 (0.56)	33.4 (0.4)	35.5 (2.2)	.72 (.04)
Age														
< 85 years	203	17.5 (0.5)	9.5 (0.8)	43.1 (1.2)	74.1 (1.3)	9.6 (0.5)	11.7 (0.3)	6.9 (0.3)†	36.6 (0.7)	−1.7 (0.6)	0.61 (0.58)†	34.1 (0.6)	36.8 (2.4)	.79 (.04)†
≥ 85 years	206	17.5 (0.7)	9.5 (0.9)	42.2 (1.5)	75.9 (1.2)	9.1 (0.4)	12.0 (0.2)	6.4 (0.2)	37.3 (0.6)	−3.4 (0.6)	−0.86 (0.62)	33.3 (0.6)	34.1 (2.4)	.70 (.05)
Gender														
Male	88	18.1 (0.6)	10.8 (1.4)	43.6 (1.5)	75.8 (1.8)	8.9 (0.5)	11.9 (0.4)	6.4 (0.4)	37.0 (0.8)	−2.7 (0.9)	−0.36 (0.86)	32.8 (0.6)	33.1 (3.2)	.72 (.05)
Female	333	17.3 (0.5)	9.1 (0.6)	42.5 (1.0)	75.0 (1.0)	9.5 (0.4)	11.9 (0.2)	6.7 (0.2)	36.9 (0.6)	−2.3 (0.5)	0.09 (0.49)	33.8 (0.5)	36.0 (2.2)	.75 (.04)
Race														
White	338	17.3 (0.4)	9.1 (0.7)	42.2 (1.0)	74.4 (1.0)	9.3 (0.4)	11.8 (0.2)	6.8 (0.2)†	36.8 (0.6)	−2.5 (0.6)	−0.18 (0.52)	33.5 (0.5)	34.8 (2.0)†	.75 (.04)
Non-White	35	17.8 (1.6)	10.2 (1.7)	44.1 (3.0)	78.9 (2.8)	10.4 (1.2)	12.2 (0.5)	5.6 (0.5)	38.4 (1.5)	−2.1 (1.6)	0.85 (1.60)	35.2 (1.6)	49.3 (5.2)	.70 (.15)
Married														
Yes	52	18.3 (0.9)	11.0 (2.1)	43.7 (2.0)	72.1 (2.5)	9.0 (0.8)	11.2 (0.4)	7.4 (0.5)†	36.5 (1.3)	−3.9 (1.0)	−1.65 (0.92)	31.2 (0.9)**	32.8 (4.2)	.68 (.09)
No	279	17.1 (0.4)	9.2 (0.7)	42.1 (1.1)	75.2 (1.2)	9.6 (0.4)	12.0 (0.2)	6.6 (0.2)	36.9 (0.6)	−2.1 (0.6)	0.25 (0.55)	34.3 (0.6)	37.7 (2.5)	.75 (.04)
Cognitive impairment														
Mild to moderate	152	17.5 (0.4)	9.5 (0.6)	42.8 (1.0)	82.4 (1.1)***	11.1 (0.6)***	12.5 (0.3)**	5.8 (0.3)***	40.6 (0.7)***	−2.1 (0.8)	1.65 (0.73)**	36.1 (0.8)***	44.3 (3.2)***	.92 (.05)***
Severe to very severe	259	—	—	—	71.1 (1.1)	8.4 (0.4)	11.5 (0.2)	7.1 (0.2)	34.9 (0.6)	−2.6 (0.6)	−0.93 (0.54)	32.3 (0.5)	31.6 (1.8)	.66 (.05)
Behavioral symptom														
None	141	16.9 (0.5)	9.0 (0.8)	41.3 (1.3)	79.1 (1.2)***	10.1 (0.6)**	12.1 (0.3)*	5.9 (0.3)***	38.2 (0.7)**	−2.5 (0.9)	0.33 (0.85)	34.7 (0.7)*	41.3 (3.2)*	.87 (.04)***
≥ 1	206	17.8 (0.5)	9.9 (0.8)	43.5 (1.3)	71.9 (1.4)	8.9 (0.5)	11.6 (0.3)	7.2 (0.3)	35.9 (0.7)	−2.3 (0.7)	−0.22 (0.60)	33.1 (0.6)	33.6 (2.4)	.66 (.06)
Functional impairment														
0–4 ADLs	198	17.4 (0.4)	9.3 (0.7)	42.1 (1.1)	78.3 (1.3)***	10.5 (0.6)***	12.1 (0.2)	6.3 (0.3)	39.6 (0.7)***	−3.2 (0.8)	0.22 (0.71)	35.0 (0.6)***	39.2 (2.7)†	.87 (.03)***
5–7 ADLs	164	17.1 (0.8)	9.1 (1.5)	42.2 (1.8)	70.6 (1.3)	8.3 (0.4)	11.5 (0.3)	7.1 (0.3)	33.7 (0.6)	−1.5 (0.6)	−0.29 (0.58)	31.9 (0.6)	32.5 (2.3)	.59 (.06)
Comorbidity														
0–2	230	17.6 (0.4)	9.1 (0.7)	43.6 (1.1)*	75.2 (1.2)	9.3 (0.5)†	11.9 (0.2)	6.5 (0.3)	37.0 (0.6)	−2.6 (0.6)	−0.20 (0.60)	34.2 (0.5)	37.5 (2.5)	.81 (.03)*

Table 3. (Continued)

Characteristic	N	Resident Report[a]			Direct Care Provider Report[a]							Observation[a]		
		DQOL (n = 100)	QOL in AD–Activity (n = 110)	QOL-AD (n = 120)	ADRQL (n = 410)	QOL in AD-Activity (n = 400)	QOL in AD–Positive Affect (n = 403)	QOL in AD–Negative Affect (n = 383)	QOL-AD (n = 410)	QOL-AD, Raw Change[a] (n = 402)	QOL-AD, Adjusted Change (n = 402)	PGC-ARS (n = 333)	DCM, % BCC Type I (n = 333)	DCM, WIB (n = 333)
≥ 3	131	16.6 (0.6)	9.5 (1.2)	40.0 (1.5)	74.9 (1.5)	9.3 (0.5)	11.8 (0.3)	6.8 (0.3)	36.8 (0.8)	−2.1 (0.8)	0.25 (0.77)	32.9 (1.0)	34.4 (2.7)	.65 (.07)
Depressed														
No	261	17.3 (0.4)	9.7 (0.7)	42.3 (1.0)	77.2 (1.1)***	9.6 (0.4)	12.1 (0.2)**	6.2 (0.2)***	37.6 (0.6)***	−2.2 (0.6)	0.40 (0.60)*	34.3 (0.6)†	38.5 (2.6)**	.77 (.04)†
Yes	86	17.1 (1.6)	6.9 (1.4)	41.9 (3.1)	67.8 (2.1)	8.9 (0.6)	11.0 (0.4)	8.0 (0.5)	34.5 (1.0)	−2.7 (0.9)	−1.21 (0.86)	32.0 (0.8)	30.7 (3.3)	.64 (.08)

Notes: DQOL = Dementia Quality of Life; QOL in AD = Quality of Life in Alzheimer's Disease; QOL-AD = Quality of Life–Alzheimer's Disease; ADRQL = Alzheimer Disease Related Quality of Life; PGC-ARS = Philadelphia Geriatric Center Affect Rating Scale; DCM % BCC = Dementia Care Mapping Behavior Category Code (percent of Type I observations); WIB = well- or ill-being; ADLs = activities of daily living. Table values are mean (*SE*). For resident-reported measures, standard errors are adjusted for clustering within facility; for direct-care-provider-reported measures, standard errors are adjusted for clustering within care provider and facility; for observed measures, standard errors are adjusted for clustering within observer and facility. The *N*s at the top of each column indicate the total number with data for that quality-of-life measure. Due to missing data on resident characteristics, the sample size for measures derived from resident report ranged from 87 to 120, direct care provider report varied from 302 to 410, and those derived from observation ranged from 263 to 333. Higher scores indicate better quality of life, except for one item: direct care provider report, QOL in AD–Negative Affect.

[a]With the exception of comparing the overall mean to zero with a paired *t* test, statistical comparisons were not made on raw change.

*p < .05; **p < .01; ***p < .001; †p < .10, adjusted for clustering as noted above.

positively related to care provider-rated and observed quality of life. Finally, family involvement was related to higher QOL in AD–activity, as rated by care providers.

Discussion

Just as the measurement of quality of life is complex and multifaceted (Sloane et al., 2005, this issue), so too is the study of how care relates to quality of life. On the one hand, some argue that such study requires longitudinal assessment, assessing care at baseline, and quality of life at baseline and follow-up, and then relating care to change in quality of life (Gonzalez-Salvador et al., 2000; Ready & Ott, 2003). Only one other study has completed a longitudinal assessment of dementia quality of life in long-term care (using the ADRQL), finding a small (5 percentage points) and potentially clinically inconsequential decline in quality of life over 2 years (with some residents showing improved quality of life over time); further, there was no association between change and resident status at baseline (Lyketsos et al., 2003). Using a different measure, the 15-item QOL-AD (ranging from 15 to 60, with a baseline mean of 36.9, *SE* 0.5), the current study similarly found little (albeit significant) change over time (raw change −2.4, *SE* 0.05, p < .0001), and for 36% of the residents, improvement of at least one point over the 6-month study interval. The authors of the ADRQL study postulated that the lack of decline in their sample might reflect the high quality of care in the one facility in which their study was conducted— which hypothetically moderated the expected decline—and called for a comparative study to tease out such relationships.

The present study of care provided to 421 residents in 45 facilities was designed to do just that. At follow-up, residents fared better in facilities with specialized workers, with more staff training in more areas (supervisor and direct care staff), and that encouraged activity participation more frequently. Specifically, mean raw change was −1.3 (*SD* 7.4) versus −3.0 (*SD* 8.2) in facilities with specialized workers compared to those without. In facilities in which 75% or more of supervisors were trained in at least five of the six domains, raw mean change was −1.0 (*SD* 8.3) versus −3.4 (*SD* 7.5); comparable figures for care provider training were −0.4 (*SD* 7.6) vs −3.5 (*SD* 7.9). In facilities that encouraged activities once a day or more, it was −1.9 (*SD* 7.8) versus −2.6 (*SD* 8.0). Interestingly, these are all facility-level variables, and none of the resident-level components of care related to change in quality of life. On the one hand, such findings are promising because they imply that facility-wide change can impact resident well-being; on the other, they call into question the degree to which individualized care is benefiting residents with dementia. It must be acknowledged, however, that this study may not

Table 4. Statistically Significant Covariate Adjusted HLM-Based Tests of Association Between Facility-Level Components of Care and Quality of Life

Facility-Level Component of Care	Resident Report			Direct Care Provider Report							Observation		
	DQOL (n = 84)	QOL in AD–Activity (n = 92)	QOL-AD (n = 101)	ADRQL (n = 302)	QOL in AD–Activity (n = 296)	QOL in AD–Positive Affect (n = 296)	QOL in AD–Negative Affect (n = 281)	QOL-AD (n = 301)	QOL-AD, Raw Change (n = 295)	QOL-AD, Adjusted Change (n = 295)	PGC-ARS (n = 245)	DCM, % BCC Type I (n = 245)	DCM, WIB (n = 245)
Demographics													
For profit						+*		+*				−*	
Chain											−*		
SCU-EQS			+*				+**	−**				+**	
AL-EQS			+*			−*		−***				+**	−*
Staffing													
Stability				−**	−**		+**	−**					
Specialized worker	−*				+*				+*	+**			
RN or LPN (contract)			−*										
Aide (contract)		+**		+**									
RN and LPN turnover												−*	+*
Policies and practices													
Admission policies	−*					+**		+*					
Discharge policies						+*							
Accept problematic behavior													
Policy choice				+**		+**							+*
Care planning													
Professional staff			+**								+**		
Aide			+*					+*			+*		
Training													
Supervisor									+***	+**			
Care staff									+***	+*		−**	
Assess													
Professional												+*	
Standardized													+*
Treat													
Professional	−**		−*			+*		+*				−*	
Other, informal	−*												
Perceived success												+**	
Use of antipsychotic or sedative hypnotic	−*		−***									−*	
Encourage activities			+*						+**	+**			
Use of stimuli					−**								

Notes: HLM = hierarchical linear model; DQOL = Dementia Quality of Life; QOL in AD = Quality of Life; QOL in AD = Quality of Life in Alzheimer's Disease; QOL-AD = Quality of Life–Alzheimer's Disease; ADRQL = Alzheimer Disease Related Quality of Life; PGC-ARS = Philadelphia Geriatric Center Affect Rating Scale; DCM % BCC = Dementia Care Mapping Behavior Category Code (percent of Type I observations); WIB = well- or ill-being; SCU-EQS = Special Care Unit Environmental Quality Scale; AL-EQS = Assisted Living Environmental Quality Scale; RN = registered nurse; LPN = licensed practical nurse. The sample size at the top of each column is the number of residents with data on that quality-of-life measure and all the covariates. Sample sizes vary among the rows from 71 to 101 for resident-reported quality of life, 241 to 302 for care-provider-reported quality of life, and 211 to 245 for observed quality of life. Columns with a "+," or "−," indicate positive and negative associations, respectively, based on hierarchical linear models with the specified quality-of-life measure as the dependent variable. For resident-reported measures, models included random effects for facility. For care-provider-reported measures, models included random effects for facility and care provider (nested within facility). For observed measures, models included random effects for facility and observer. Associations were additionally adjusted for facility type (RC/AL vs nursing home) and resident gender, cognitive deficit, behavioral symptoms, ADL impairment, comorbidity, and depressive symptoms; associations with care provider report and observed measures were further adjusted for resident tenure, age, race and marital status. Facility type; size; age; affiliation; percent dementia beds; dementia and ADL impairment case-mix; universal worker; RN, LPN, and aide FTEs; administrator and aide turnover; and extent hire for experience were not significantly associated with any quality-of-life measures (p > .10).

*p < .10; **p < .05; ***p < .01.

Table 5. Statistically Significant Covariate Adjusted HLM-Based Tests of Association Between Resident-Level Components of Care and Quality of Life

Resident-Level Component of Care	Resident Report			Direct Care Provider Report							Observation		
	DQOL (n = 84)	QOL in AD–Activity (n = 92)	QOL-AD (n = 101)	ADRQL (n = 302)	QOL in AD–Activity (n = 296)	QOL in AD–Positive Affect (n = 296)	QOL in AD–Negative Affect (n = 281)	QOL-AD Raw Change (n = 301)	QOL-AD Raw Change (n = 295)	QOL-AD, Adjusted Change (n = 295)	PGC-ARS (n = 245)	DCM, % BCC Type I (n = 245)	DCM, WIB (n = 245)
Reported and observed care													
Dementia area										–*			
Cholinesterase inhibitor					+*					+*	+*		
Restraints, ever[a]	NA	NA	NA									–***	
Ungroomed appearance			–**		–**					–*	–*	–***	–***
Staff experience, perceptions, and observed behavior													
Approaches													
Total	+**	+*		+**		+**							
Hope	+***	+**											
Person-centered				–*		+**		+**					+**
Work stress													
Work satisfaction				+*	+*								
Communication				+***	+***						+***	+***	+***
Personal detractors									–*		–***	–***	–***
Positive person work				+***		+**					+**	+***	+***
Physical contact				+*								+***	+**
Family involvement				+***									

Notes: HLM = hierarchical linear model; DQOL = Dementia Quality of Life; QOL = Quality of Life; QOL in AD = Quality of Life in Alzheimer's Disease; QOL–AD = Quality of Life–Alzheimer's Disease; ADRQL = Alzheimer Disease Related Quality of Life; PGC-ARS = Philadelphia Geriatric Center Affect Rating Scale; DCM % BCC = Dementia Care Mapping Behavior Category Code (percent of Type I observations); WIB = well- or ill-being. The sample size at the top of each column is the number of residents with data on that quality-of-life measure and all the covariates. Sample sizes vary among the rows from 63 to 101 for resident-reported quality of life, and 198 to 245 for observed quality of life, 220 to 302 for care-provider-reported quality of life. Columns with a "+" or "–" indicate positive and negative associations, respectively, based on hierarchical linear models with the specified quality-of-life measure as the dependent variable. For resident-reported quality-of-life measures, models included a random effect for facility. For care-provider-reported quality-of-life measures, models included random effects for facility and care provider (nested within facility). For observed measures, models included random effects for facility and observer. Associations were additionally adjusted for facility type (RC/AL vs nursing home) and resident gender, cognitive deficit, behavioral symptoms, ADL impairment, comorbidity, and depressive symptoms; associations with care provider report and observed measures were further adjusted for resident tenure, age, race and marital status. Unsuitable appearance and experience of supervisor and direct care staff were not significantly associated with any quality-of-life measures (p > .10).

[a] Association of restraint use with resident-reported quality of life cannot be estimated, as those residents reporting quality of life were never observed in restraints.

*p < .10; **p < .05; ***p < .01.

have had sufficient power to detect some of these associations—but even if it did, they likely would have been small, and, similar to the ADRQL study, of questionable clinical relevance. Nonetheless, considering this acknowledged limitation, the fact that three components of care related to change over time may highlight the utility of turning attention to the areas of specialized workers, staff training, and encouragement of activity participation. In one area this attention may spark debate, as many states promote the practice of universal workers (Mollica, 2002), and the expanded use of specialized workers may change demands for care.

The authors of the ADRQL study concluded that the ADRQL is sensitive to change over time (although noted that such sensitivity might be limited) and appropriate for use as an outcome measure in intervention studies. In the current study, change in quality of life measured with the QOL-AD was significantly different over an even shorter period of time (6 months as opposed to 2 years); also, it detected a significant relationship with cognitive and affective status (such that a more favorable status at baseline related to relatively better quality of life at follow-up) and was markedly lower for residents immediately before the time of discharge or death compared to those who remained in the facility through 6 months (raw change −4.7 [*SD* 7.7] vs −1.7 [*SD* 7.9]). Finally, the fact that the QOL-AD detected differences among components of care further merits its consideration as an outcome measure. It might be a particularly useful measure if interest was in how the resident rated his or her quality of life, as the patient version of the QOL-AD can be reliably and validly completed by those with a MMSE score as low as 10; the degree to which this version is sensitive to change is unknown, however (Logsdon, Gibbons, McCurry, & Teri, 2002).

If one were of a different mindset, one would recognize that a longitudinal study comparing care to quality of life in a cohort of current residents (as opposed to a new admissions cohort) may be insensitive to the effects the care environment had exerted since the time of admission. In such a case, a cross-sectional comparison of care to quality of life, adjusting for resident status, might best indicate this relationship. In making those comparisons, this study found many associations of care to outcomes; given the multiple comparisons, it is best to focus on the detected patterns.

The 11 measures used in this study define quality of life differently and from three different vantage points. None constitutes a gold standard, although many suggest that the resident's point of view should take priority (Brod et al., 1999). In this study, we could conduct analyses for at most 120 resident reports, and significant associations with so modest a sample are worthy of discussion. From the resident's perspective, quality of life was higher for those in facilities that more frequently involved more staff in care planning and whose care providers felt more hope (e.g., that residents can make decisions, that they will not inevitably go ''down hill,'' and that feeling attached to residents need not be avoided). Also, quality of life was lower in facilities that provided more treatment, including antipsychotic and sedative hypnotic medications, and when residents themselves were ungroomed. Other authors have found a relationship between anxiolytic treatment and reduced quality of life, and the likely explanation is that more intense treatment is used (not entirely successfully) for residents who are more impaired (a relationship that persisted despite controlling for resident status in these analyses; Gonzalez-Slavador et al., 2000).

A limitation of relating care provider assessments of quality of life to outcomes is that such assessments are influenced by caregiver factors (Gonzalez-Slavador et al., 2000; Karlawish, Casarett, Klocinski, & Clark, 2001; Winzelberg, Williams, Preisser, Zimmerman, & Sloane, 2005, this issue). Thus, it may come as no surprise that residents with whom workers communicate more and toward whom they display positive person work (e.g., enable the resident to do what he or she couldn't otherwise do) tend to be rated more highly. One finding to note is that these same interpersonal components are related to observational indicators of quality of life, such that these residents display more positive affect, behaviors, and general well-being. Thus, to the extent that workers have the time and can feel and act positively toward residents, quality of life is likely to be improved. Further, these attitudes relate to worker satisfaction as well, and so all parties may benefit when positive interactions are maximized (Zimmerman, Williams, et al., 2005, this issue). Finally, contrary to conventional wisdom, more stability in staff–resident assignment was related to worse staff ratings of quality of life (but not to resident or observer ratings of quality of life). Whether stability is affecting care provider attitudes (and hence ratings), or whether it is actually affecting resident quality of life is not known. A recent study showed no clear superiority of permanent versus rotating staffing, and so this area merits further attention (Burgio, Fisher, Fairchild, Scilley, & Hardin, 2004).

Finally, it would be remiss to not stress the fact that (a) resident appearance was related to at least one measure of quality of life as rated by residents, care providers, and observation, and (b) facility type (RC/AL vs nursing home) and number of dementia beds were not related to any quality-of-life measures. Grooming may be an inherent indicator of dignity and, as such, may be an implicit marker of poor quality of life. As far as setting of care, there is increasing evidence that the quality of care in nursing homes has been improving (Feldman & Kane, 2003) and no overwhelming indication that special dementia care is related to better outcomes (Phillips

et al., 1997). Thus, while RC/AL developed in part so that older adults could avoid nursing home placement, the tide may have turned, and these settings may be less different than some consider—and equally suitable (although perhaps not equally affordable) for the care of residents with dementia (Kane & Wilson, 2001; Zimmerman et al., 2003). At minimum, it is likely that such gross categorizations of care (RC/AL, nursing home) do not relate to differences in care that are affecting resident quality of life.

What then do these myriad findings suggest? They certainly suggest directions for hypothesis generation and further exploration and evaluation. While causal attribution is not possible, the findings suggest that facilities should consider (and studies should evaluate) using a specialized worker perspective, train all staff in domains central to dementia (depression, pain, behavioral symptoms, ambulation, nutrition, and hydration), and encourage activity participation (related to change in quality of life over time). They suggest that attention be paid to resident grooming (related to quality-of-life ratings by residents, staff, and observation). They suggest that facilities should involve staff in care planning, encourage care providers to feel more hope, and avoid antipsychotic and sedative hypnotic medications, if possible (related to resident perceptions of quality of life). They suggest that staff should communicate more, and positively, with residents (related to care provider rating and observed quality of life) and that rotating worker assignment be further explored (related to care provider rating). To the extent that all of these areas are under the control of the facility, and can be implemented with few new resources, all are worth consideration and evaluation to improve the quality of life of long-term care residents with dementia. In fact, the Alzheimer's Association is undertaking a national educational campaign, the Campaign for Quality in Residential Care, to implement and evaluate many of these components of care. Thus, the growth of evidence-based practice to improve the quality of life for residents with dementia in long-term care is evident, and promising.

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THE GERONTOLOGIST
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